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TRANSNATIONAL RESPONSES TO AIDS
AND THE GLOBAL PRODUCTION OF SCIENCE:
A CASE-STUDY FROM RIO DE JANEIRO

by

CRISTIANA BASTOS

A dissertation submitted to the Graduate
Faculty in Anthropology in partial fulfillment
of the requirements for the degree of Doctor
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Abstract**TRANSNATIONAL RESPONSES TO AIDS AND THE GLOBAL PRODUCTION
OF SCIENCE: A CASE STUDY FROM RIO DE JANEIRO****by****Cristiana Bastos**

Adviser: Professor Vincent Crapanzano

AIDS challenged most assumptions about the medical defeat of infectious diseases. A global health problem replaced the traditional contrast between the epidemic-free developed world and the infectious diseases ridden developing countries. In the U.S., communities burdened with the impact of AIDS reacted to the absence of a medical cure by creating their own expert knowledge on prevention, support, drug development, clinical trials, and basic science. The interaction between this social movement and the scientific establishment generated new formulas for treatment and research. To implement action throughout the world, WHO created the Global Programme on AIDS. GPA's influence raised awareness about the social dimensions of AIDS and promoted alliances between the different social partners involved in the fight against the epidemic. With a

transnational and transdisciplinary rhetoric, the agency built partnerships with local governments, non-governmental organizations, and research agencies. For a period, the movement lived an atmosphere of "health revolution."

Asking whether these innovations might have a real impact in the global production of knowledge about AIDS, I conducted ethnographic research among medical, scientific and activist settings in Rio de Janeiro, Brazil, chosen due to its well-connected albeit peripheral situation within the world system, plus its autonomous production of biomedical science with a strong component of infectious disease, social medicine, and epidemiology.

Research showed that during the period of 1989-90 networking and interdisciplinary efforts energized the action against AIDS in the local as in the global setting. However, after the replacement of WHO's revolutionary commitment by a more medicalized approach to AIDS, the efforts towards a major transformation declined worldwide. The social forces involved in the struggle became fragmented; the transnational alliances reproduced dependency in situations of scarce resources; knowledge flows followed hierarchical patterns; each discipline retreated to its specialty; overwhelming clinical demand competed with research. Some of the transformative ideas and the possible basis for a paradigm shift in immunology and infectious disease remain very close, yet on the side, of the field of AIDS.

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The questions that generated this research matured in the years 1987-1989 while I attended graduate school in New York. The city was swept by the AIDS crisis. It was a priority topic for students of medical anthropology. Since this crisis turned upside-down some of our assumptions regarding biomedicine, infectious disease, the immune system, and epidemiological patterns, I thought the problem should (also) be contextualized within a discussion on the cultural construction of medical knowledge. I owe my first steps into that reflection to Professor Shirley Lindenbaum, then at the New School, with whom I took stimulating courses in medical anthropology, maintained a regular discussion, and received constant support in all kinds of situations, including proposal writing, field aftermath, and dissertation production. My questions were rooted in a broader problem on the social production of knowledge that could account for the asymmetries within the world system. Having formulated this problem earlier in another context, Professor Vincent Crapanzano helped me frame my own version of it and provided a creative, permanent and supportive supervision to which this final result owes so very much.

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I chose Brazil not only for the reasons included in the argument regarding its particular situation in the world system and its role on the production of knowledge. The choice was also due to the welcoming environment experienced in my first trip there in 1989, realized after a suggestion from my friends and fellow anthropologists

Ligia Simonian and Antonio Carlos Souza Lima, and with the support of CUNY Research Foundation. Besides providing constant guidance and a wonderful friendship, Souza Lima also introduced me to the Graduate Program in Social Anthropology in **Museu Nacional**, UFRJ, where I benefited from the courses of Prof. Gilberto Velho and Prof. Roberto Cardoso de Oliveira, as well from the interaction with Profs. Luiz Fernando Dias Duarte, Otávio Velho, Ana Dao, and other student and faculty members. In the **Social Medicine Institute** of the State University of Rio de Janeiro I had the privilege of meeting Sérgio Carrara and count on his unlimited friendship in all different situations, and Richard Parker, who welcomed my project and provided support all throughout its long periods. It was there that I also met Kenneth Camargo, Maria Andrea Loyola, Luiz Antonio de Castro Santos, Marilena Corrêa, Barbara Musomeci, Santuza Ribeiro, and a stimulating research atmosphere. In **ABIA** I met an extraordinary number of bright, engaged and friendly people who gave me persistent support: Carmen Dora Guimarães, Silvia Ramos, Herbert Daniel, Ranulfo Cardoso, Flavio Wiick, Walter Almeida, Veriano Terto, José Stalin Pedrosa, Jane Galvão, José Carlos Lopes, Christina Valinotto, Cristina Castelo Branco, Nelson Solano, Lys Portella, Jacques Schwarzstein, Jean-Luc, Neuci, Sergio, Marcio, Cesar, Tania, and the many others that worked there one time or another. The Pela VIDDA group let me participate in their activities. Rather

than single out names, which are just too many, I am indebted to the collective atmosphere of creative responses, mutual support, and political awareness that moved this organization. Other NGOS generously opened their doors and helped me become familiar with the local situation. To Ana Filgueiras, who also dragged me along to her international networks, a special thanks. Thanks also to other assorted **cariocas** that gave me fragments of life in Rio in the time of AIDS: Fernanda, Flávio, Gil, Márcia Rachid, Márcias, Nilton, Paulo Longo, Paulo, Ricardo, Roberto Bacelar, Sandra, Sylvio, Zé.

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the people acknowledged above are no longer with us; to them, and to those struggling to remain, I dedicate this work.

TABLE OF CONTENTS

Introduction.....	1
Chapter 1: AIDS and Science.....	14
Chapter 2: Politics and the Construction of Knowledge: AIDS Activism as a New Social Movement.....	62
Chapter 3: Sponsoring Global Action: The Role of WHO....	124
Chapter 4: Local Action: Responding to AIDS in Brazil...	168
Chapter 5: Central Problems in a Peripheral Landscape: Negotiating Knowledge and Treating AIDS in Brazilian Medical Settings.....	225
Chapter 6: War Metaphors in Germ Theory and Immunology: In Search of a New Paradigm.....	288
Conclusions.....	325
References.....	342

INTRODUCTION

Unexpected and unexpectedly, the AIDS epidemic caught urban America in one of its most flamboyant and prosperous periods ever, the 1980s. The new disease challenged the power of medicine and pushed the limits of medical knowledge, showing how illusory the history of irreversible victories against infectious disease had been. Death, defeat and collective mourning became a constant experience in communities which hardly known them before. In response to a medical crisis that was also evidence of the limits of the existing biomedical research, many in the affected communities got actively involved and developed an entirely new social movement. My work will focus on the encounter between different social partners in the process of producing knowledge relevant to the AIDS crisis. Arguing for the creative and transformative potential of those encounters, the analysis will include two levels: the interaction between the AIDS social movement and the medical establishment, and the transnational partnerships formed in the context of an officially defined global pandemic.

From a social sciences perspective, AIDS raises simultaneously two important sets of issues concerning the

shape and nature of current biomedical knowledge, its limits, perspectives, and modes of production, as well as the contradictions and fractures in the contemporary global society. My analysis will integrate the two problems as they were revealed by the AIDS crisis.

A linear narrative, academic or not, cannot fully contain the issues this crisis raises, as so many reverberating effects unfold into so many directions. Overloaded with competing messages and with multiple, first-person accounts of direct experience, the field of AIDS combines its own discursive production with a diverse range of external analytic undertakings. Knowing that no single analysis can do justice to that contradictory complexity, my approach is composed of a series of approaches to the subject, where the task of analyzing the new knowledge produced in the context of AIDS is an attempt to identify the social actors involved in its production and locate them within the contemporary world-system.

After an overview of the state-of-the-art production of biomedical knowledge and social commentary on it, the text will include an analysis of the social movement generated by the inability of the medical establishment to efficiently respond to the AIDS crisis. That account is

followed by an examination of the level of awareness of the global dimensions of the epidemic and of the efforts of international agencies to create the material possibility of global responses. The text then moves to a field setting in which the current asymmetries of the world are overwhelmingly present -- contemporary urban Brazil -- in order to evaluate the extent to which the global responses to the epidemic are accompanied by interactive structures attempting to bridge global gaps and create the conditions for the production of transformative knowledge.

How was this research accomplished? Not through the traditional 18-months residence in a field community, but not by dismissing it either. An 18-month period in a previously unknown site was a central component of the research, even though integrated into a number of experiences that preceded and followed it. Direct contact with the social movement responding to AIDS in the late 1980s was the result of moving to New York City in 1987, where anyone was a observer of and often a participant in the process. To attend ACT UP demonstrations and meetings, to know the literature and handouts produced by the different agencies created to respond to AIDS, to be directly touched by the epidemic, were part of just existing, then and there, with some level of social and political awareness. Not having been formally involved with New York AIDS agencies as a researcher, volunteer, or staff

member, my knowledge about them is processed neither as "data" nor as "insiders knowledge," but rather as that of someone who witnessed the movement from a very close perspective and tried to become as informed as possible. For that purpose I counted not only on the usual primary sources, like newsletters, handouts, leaflets, videos, films, public speeches, rallies, and word of mouth, but also on the analytic material created by the movement, which was itself full of writers, social scientists, and critical theorists. From them come many of the references and inspiring sources of chapter 2 (e.g. Aggleton et al. 1989, 1990, 1991, 1992, 1993, Crimp 1987, 1990, Elbaz 1990, 1991, 1992, Harrington 1994, Kramer 1989, Mass 1990a, Patton 1985, 1990, Watney 1994, Wolfe 1994). Complementing those sources were a few journalistic accounts of the epidemic and its responses in America, based on primary research (Arno and Feiden 1989, Burkett 1995, Panem 1988, Nussbaum 1990, Shilts 1987). Contact with this large body of printed production on the epidemic, almost in simultaneity with the events, helped blur the boundaries between direct observation and a more academic type of learning. Throughout the different moments of research, including the formal "fieldwork" in Brazil, I would go back to this "observation/learning mode"; I re-thought it throughout the period of processing the "research data," that is, the observations recollected in a formal "field

setting." Necessarily, the boundaries of these bodies of knowledge blurred and shifted.

The "global setting," a constant presence throughout the text that is treated separately in chapter 3, was a more "ethereal" field site. A discursive construction, certainly, but a political site as well, with material and cognitive extensions in the matters of international funding and the development of global awareness, this site had a physical existence in ritual moments like the international conferences on AIDS, as well as a bureaucratic appearance in the international agencies headquarters, and a knowledge defining stance in the global reports produced by the latter.

The international agencies linked to development, external aid, and the U.N., oriented since World War II towards understanding and alleviating the painful gaps in the world, took on the double task of defining the global dimensions of AIDS and of framing the regional, macro differences in the experience of the pandemic. It was their action-oriented knowledge, rather than the callous work of anthropologists theorizing about world heterogeneities, that first approached the diversity of experiences in this universal problem. Responding rapidly to the prospect of a global health crisis, WHO created the Global Programme on AIDS. In 1988, it systematized the diversity of forms of

the epidemic in a 3-pattern model. From then on, there would be the "pattern I," "pattern II" and "pattern III" countries, or regions. In popular knowledge and in the media this model was equated with an opposition between a "developed countries pattern," centered on homosexual and drug-related transmission, and a "developing countries pattern," centered on heterosexual transmission, plus a large pattern-block with no reported cases and yet the potential for an epidemic explosion. The key concepts for defining those patterns, and their popular/mediatic interpretation, were based on individual behavior and drawn from the cultural categories of the urban centers where the epidemic had first been diagnosed.

This raised a problem only too familiar to those who approach the deconstruction of scientific knowledge: the very description of the worldwide epidemic that I needed as an instrument for further analysis was itself a social construction. In 1988/89 I discussed this problem in a paper on the cultural construction of epidemiology. The need to substantiate the points transformed the paper into a research proposal which brought me to Brazil, where the definition of AIDS epidemiology was itself a battleground for dissent, criticism and negotiation, as it was expressed in the works of social scientists and political writers (Daniel 1985, Guimarães et al. 1988, Moraes and Carrara 1985a, Parker 1987).

In the two preliminary field trips to Brazil in 1989 and 1990 I contacted the local institutions where this critical stance was more visible: ABIA, the Brazilian Interdisciplinary AIDS Association, a Rio-based NGO created in late 1986, and the Social Medicine Institute, a department of the State University of Rio de Janeiro oriented towards the convergence of the health and the social sciences. I also contacted other local academic departments, activist organizations and health services in order to plan fieldwork. Fieldwork lasted from December 1990 to May 1992, and was the closest to the traditional concept of fieldwork, albeit urban and scattered through the areas and institutions of a modern metropolis like Rio de Janeiro. It was supplemented by short visits to other cities like São Paulo, Salvador, Belo Horizonte, and Brasília. Experiencing different places made me cautious about generalizing: none of them replicated the others, and my conclusions are quite a function of having been based in Rio and not in São Paulo or elsewhere. Expanding the diversity of social actors contacted made me go beyond the discussion on the cultural construction of epidemiology to the broader aspects of medical knowledge that had interested me in the first place. I finally gave priority to the analysis of basic science, also paying attention to clinical knowledge. A similar focus was given by an important component of AIDS activism in New York City that

dedicated time and energy to the examination of immunology and the biology of infectious disease. It seemed at that point that this was the site for a leap in knowledge that might have a significant impact on AIDS. After examining the creative interactions between different social partners like activists and scientists in urban North America, I looked for the potentially creative interactions between local medical research and mainstream international research. Concentrating initially on a University Hospital AIDS unit that combined medical care and research (UFRJ), I moved later to a biomedical research center that covered other areas of infectious disease and immunology research (FIOCRUZ).

Hospitals, NGOs, government offices, health centers, and research institutes provided the reference sites for the definition of the terrain. Leisurely places and activities completed the understanding of the local issues. Informal conversations were combined with formal interviews. Institutional moments of definition and evaluation, like scientific and organizational meetings, provided structured self-portraits of the process. Participation in the daily life of the agencies and health care centers permitted the anthropological exercise of

capturing the unpredicted and using it to structure knowledge on the subject. Printed matter and reflection were at once sources of information and subjects for analysis and dialogical interaction with "informants" turned interlocutors.

Fieldwork was indeed scattered, which increased the proverbial field anxieties about methods, data, and the analytic objectification of a subjective experience. Those minor worries overlapped with a more direct and brutal experience of the effects of the epidemic among people I got to know and became friends with throughout the period of research, which also sharpened my perception of the universality of the experiences brought by AIDS concerning death, fear, impotence, or willingness to act, so similar to those of New York. Some other things were experienced differently, and they might be subject to cultural analysis: differences in the style of social responses; in the interactions between society and government; between social organizations and the medical establishment; between patients and doctors; between people with AIDS and their treatments; and between the public and information on AIDS. Those differences added to contrasts in patterns of sexuality, drug use, blood distribution, and other transmission related issues, which had already been analyzed by social scientists.

And yet those contrasts could not be fully analyzed in a dual cross-cultural comparison between, for instance, the

responses to AIDS in New York and Rio. More than just being "cultural contrasts," these differences were mediated by the asymmetries of the world system. This problem, latent in my initial question, grew increasingly visible as the analysis proceeded. AIDS was primarily defined as an international issue, and by that very fact the representation of the diseases encapsulated the asymmetries within the contemporary world system. This aspect could not be left out of the analysis. Local commentary perceived and elaborated on the topic: as some Brazilian analysts noted, "**aids**-the-phenomenon" arrived in the country before "AIDS-the-disease" (Ramos 1990). Unlike what happens to malaria or other massive health problems, responses to AIDS in Brazil were influenced by the fact that there were responses to AIDS in the U.S. and that there was a special, global effort regarding this particular disease. From the start, responses to AIDS in Brazil were relational -- and not so much between the social movements and the medical establishment, as in the U.S., but in deriving from a permanent interaction with the international action and related networks.

This analysis helped me shape the form of this text. After approaching the theoretical problem and related literature (chapter 1), I give some background information on the international context (chapters 2-3) and offer a separate treatment of the worlds of social responses

(chapter 4), medical settings (chapter 5) and scientific research (chapter 6) in Brazil. It became increasingly clear that the interactions between each of these spheres and their international networks regarding the production and use of knowledge were more relevant than the interactions they might have among themselves, even if they coexisted in the same city, overlapped in terms of personnel, and promoted a number of joint actions. During the years that included the preliminary trips, the 18 months of fieldwork and the follow-up visits, I could observe the extent to which international references, relations, pieces of information, and direct interaction, were part of local daily life. This happened in a fractured mode, as each of the sectors had its own international network; it also had fracturing effects, by expanding the universes of interaction of the different sectors into divergent directions. At a level of knowledge production and reproduction, the staff of ABIA, for instance, had an easier connection with the Geneva-based staff of the Global Programme on AIDS than with that of the local hospitals next door, a few miles uptown, or across the bay. Each had different, specialized knowledge, and only peripheral contact with one another. Daily interaction across transnational spaces materialized in all sorts of ways: funding, networks, literature, references, connections, messages, mail, fax and electronic mail, and actual visits.

Deeply embedded in the international response, local agencies were an integrating part of international networks, and fieldwork had to include their participation in international forums.

Definitely, fieldwork was not confined to a small community. The subject constantly exploded beyond its limits, often onto worldwide levels. Unlike the physically and distinctively distant field sites of traditional anthropology, this setting was present everywhere and anywhere, a fact that increased the difficulty of finalizing fieldwork on a subject that was already unusually distressing. The text that follows is an attempt to disembody this experience using the formal language of social analysis, literature review, ethnographic account, and theoretical discussion.

Chapter 1

AIDS AND SCIENCE

Right before AIDS became noticed in the United States, and even some time into the epidemic, self-confidence and triumphalism characterized American medicine and set the tone for medical practices throughout the world (e.g. WHO 1979, 1981, 1986a). Reports and reflective articles (e.g. Knowles 1977, American Academy 1986, and particularly Thomas 1977, Fredrickson 1977, Rogers 1986) evaluated the improvement of health in America when compared to previous decades, even though those generalizations overlooked the stratification in health status that social analysis attending to class and race might evidence.

At that time, occasional references to the increase of new diseases and the deterioration of health were seen by the medical establishment as faulty propaganda. What was needed, they argued, was **more knowledge** and **more research**. With more knowledge, the remaining "mysterious" diseases like cancer, arthritis or atherosclerosis would be defeated just like infectious diseases had been in the past. Medicine would sooner or later overcome the remaining problems, even the major challenge posed by cancer. When AIDS appeared, it was seen by some of these commentators as

a distraction in the main path of the medical mission of conquering disease; some years into the AIDS epidemic, one of them lamented that

it seems probable that new drugs and vaccines will at some future date bring [AIDS] under control... [however,] in the interim, AIDS will consume the time and talents of many research scientists, and much money, and medical care resources will be **diverted** to care for those stricken with this 'disease of social change' (Rogers 1986:221, emphasis added)

The forefront of medical research was epitomized in the 1970s by the **war on cancer** (see Chubin and Studer 1978, Fredrickson 1977, Studer and Chubin 1980; see also Harden and Rodrigues 1993). Like the 1960s **war on poverty** and later the **war on drugs**, the **war on cancer** supposedly displaced towards more noble civil causes the energies and funds that supplied real military wars. As we will see in chapter 6, "war" is more than a casual metaphor. Representations frame the direction of medical research and influence decision making as well as clinical management. This way, representations are not just epiphenomenal derivatives nor irrelevant superstructural and ideological elements: they have a mediating role and a final impact on the actual course of epidemics.

Previous metaphorical wars of science against disease had brought temporary victories to humankind. Infectious diseases and the microbes that caused them had been "defeated" decades earlier by medical magic bullets like

antibiotics (See Brandt 1987), or "eradicated" by vaccination. The "conquest" of smallpox represented a landmark. Medical writer Laurie Garrett notes that the sight of victory against that disease seemed to inaugurate a new era, which brought also the decline of the specialty on infectious disease:

Surgeon general William H. Steward in 1969 told the U.S. Congress that it was time to "close the book on infectious diseases," declared the war against pestilence won, and shift national resources to such chronic problems as cancer and heart disease... Young scientists got the message that fields such as medical entomology, parasitology, and host pathology were not the paths to rewarding, productive careers. (Garrett 1992:825)

With cancer, however, there was no victory in sight. Years of research and millions of dollars invested had produced quite a number of medical articles, yet a limited understanding of the disease; there was not a major breakthrough or a **cure**, but only modest improvements in prevention through early screening, as well as more efficient and humane therapies.

One of the appealing hypotheses for basic research on cancer in the 1970s had been about its viral etiology (see Stuber and Chubin 1980), followed afterwards by the interest in molecular genetics (see Fujimura 1988). While it attracted scientific interest and funding, the pursuit of cancer-causing viruses was one of the leading programs in the National Cancer Institute. However, its outcome was

a modest one. The only major finding of the collective endeavor of "virus hunting" (Gallo 1991, Lapierre 1990, Nussbaum 1990) in cancer research was the first description of a human retrovirus, in 1980, by the team of Robert Gallo from the National Cancer Institute (NCI). The virus was named HTLV, for Human T-cell lymphotropic virus. Its significance was more important for basic science than for clinical medicine: first related to leukemia, later to lymphoma, HTLV was hard to match with recurring diseases. It corresponded, however, to the findings of a research group in Japan, where the epidemiology of viral lymphadenopathy is also higher (see Garrett 1993).

From a basic science perspective, retroviruses were a quite novel concept. Regular viruses were already an odd concept for the life-sciences, since they are neither alive nor inanimate (see Fettner 1990, Jaret 1994); but still, they are composed by the bare structure of life, the double helix chain of DNA (desoxiribonucleic acid). With that structure they can depend of living cells, get a temporary, parasitic, and "borrowed" life. They replicate at the expense of their infection. Conversely, retroviruses are composed of a single helix chain of RNA (ribonucleic acid). In theory, until the mid 1970s, such an existence was considered irrelevant for human health, as it was not supposed to replicate or cause infections. The basic dogma of biology stated that DNA (double chain) produced RNA

(single chain), but not the reverse. Retroviruses contradict the basic dogma; they reverse it by creating DNA from RNA. Retroviruses could only be officially conceived after Howard Temin and David Baltimore defined **reverse transcriptase**, which is the enzyme that allows the "inverse" replication of RNA viruses into DNA. For that discovery they were awarded the Nobel prize in 1975.¹ Like other viruses, retroviruses exist at the expense of the living cells. In the second half of the 1970s, a few animal retroviruses were identified. Now, they are known to exist in cats, sheep, bovines, and a number of primates.

Such was the set of advanced biomedical research at the time of the first reported cases of Kaposi Sarcoma in New York City in the year of 1981. Kaposi Sarcoma (KS) was considered a rare cancer that for some unknown reason

¹Virologist Emmanuel Heller, currently in Tel-Aviv after a cosmopolitan career that included the NCI, told me in an interview that during the early seventies he had witnessed replication processes that contradicted the basic dogma that only DNA produces RNA. He did not, however, dare to challenge what was the central belief of biology after Watson and Crick had defined the **double chain**. A few years later he saw Howard and Temin being rewarded with the Nobel prize for daring to do so and collecting enough evidence to make their point (Heller, personal communication, July 1992). This episode illustrates the roles of adequate timing and adequate conditions for daring to change the central models of thinking, rather than "raw" evidence, have in the transformation of scientific knowledge.

appeared in a pernicious and lethal version among New York gay men. It would become later classified as one of the pathologies of the new epidemic syndrome, "AIDS." Not surprisingly, doctors involved with the initial cases of Kaposi sarcoma in New York, such as doctor Alvin Friedman Kien (e.g. Mass 1990a:132), suggested the possibility of a viral etiology for the new disease. They became optimistic about the implications of this finding for basic research on cancer (see also Norman 1986:170). Cancer was the one challenge that modern medicine was still at odds with; the understanding of its etiology and mechanisms of pathogenesis would enrich biomedicine and also broaden the scope of human biology.

HTLV, the 1980-born product of the National Cancer Institute research, became the number one candidate for a possible cause for AIDS. While outside the laboratories all kinds of ideologies explained the new disease in terms of blame, environmental factors, God's punishment, or life-style excesses, scientists in the research agencies pursued a viral hypothesis. Among them, NCI researchers focused on HTLV. This hypothesis was however a difficult one to prove, for the laboratory viral lineages perished fast and before any conclusions could be made (see Shilts 1987).

Yet, the viral hypothesis was pursued elsewhere with success: at the Pasteur Institute in France, Dr. Françoise Barré-Sinoussi was able to grow a culture of virus from the

blood of an AIDS patient. In May 1983 she isolated the new virus "RUB", named after the patient whose blood had been used. The virus designation was replaced by LAV, for Lymphadenopathy Associated Virus. Journalist Randy Shilts quotes Robert Gallo's remark that the editor of **Science** "thought RUB was a disgusting acronym for a virus relating to this particular disease" (Shilts 1987:264).

The evidence of reverse transcriptase activity in the French-isolated virus RUB/LAV qualified it to be classified a human retrovirus, like the NCI-isolated HTLV. However, the genetic structure of LAV did not match the one described in 1980 for the original HTLV. In 1983, French researchers sent a sample of LAV to the National Cancer Institute in the U.S. in order to have it checked against HTLV. Were they the same, and therefore prove Gallo's hypothesis on the cause of AIDS? Were they different variants from the same family of viruses?

Even though the French researchers considered LAV very different from HTLV, and classified their finding as a "lentivirus," NCI researchers declared that LAV matched their own newly found AIDS-causing HTLV-III, supposedly a new variant of the already known HTLV. It took years to bring to light the unethical procedures of Gallo's team, who actually "re-baptized" LAV, serving a number of non-scientific goals that included personal vanity, nationalism and monetary profits. Also about that time, California

Researcher Jay Levy had isolated a strain of virus from blood of people with AIDS and named it ARV, for AIDS Related Virus. Lack of funding precluded the research team from having success and from participating in the "co-discovery" of the cause for AIDS (see Shilts 1987:452).

The finding of **the** agent that caused AIDS was publicly presented as a major breakthrough due to the NCI scientists. The news was given with fanfare in a media conference in April 1984. In front of the cameras, The Secretary of Health and Human Services Margaret Heckler announced "another miracle in the long honor roll of American medicine and science," the finding of the probable cause of AIDS, named HTLV-III, and described as a variant of a known human cancer virus (see Shilts 1987:450-451). The discovery was attributed to Dr. Robert Gallo from the NCI. The announcement was made in April 23, 1983, just one day after the New York Times ran a story about the French discovery of the AIDS virus (Nussbaum 1990:37-38). Instead of being announced in a scientific forum, this major scientific discovery went public in this unusual way, a spotlight on Robert Gallo and on the heroic capacities of American scientists. It also raised hopes for the finding of a cure and a vaccine in the following couple of years. Pinpointing a microbe enemy as the cause for the epidemic seemed to be the first step for a cure. With this new finding, AIDS was re-categorized as an infectious disease rather than a form of cancer.

As an infectious disease, the epidemic pattern with which it was presented made more sense. A transmissible microbe was at the basis of the epidemic clusters found among urban American gay men, drug users, Caribbeans, Africans, blood recipients, and infants.

Thereon, most research was oriented by the hypothesis of an infectious agent, and framed by the germ-theory paradigm. It would soon join the viral molecular biology "bandwagon."² Most research was dominated by the priority of knowing the "invading enemy." This priority reduced the emphasis on complementary areas of research, such as the better understanding of the infected immune-system and the variation of immune reactions in the context of AIDS.

While at a microscopic level the boundaries between cancer and infectious disease seemed to blur and eventually merge, from a macro-perspective the two illnesses were in distant positions. They had classically been assigned opposed meanings in mortality and morbidity statistics, defining a bi-polar "world health system." Cancer, like heart disease, was considered the burden of modernity; where infectious disease succumbed to adequate health care,

²Joan Fujimura (1988) has used this concept to describe U.S. Cancer research during the 1980s.

nutrition, education, and economic well being, that is, in the developed countries, cancer and heart disease stood out in the records of morbidity and mortality. In the absence of social and economic well being and other development indicators, in the more disenfranchised parts of the world, cancer numbers were submerged amidst an array of infectious diseases such as tuberculosis, malaria, cholera, schistosomiasis, leprosy, filariasis, trypanosomiasis, plague and child dysentery, to name just a few of the technically treatable or preventable diseases that still kill and frighten many populations in the world. Following a modernization paradigm, populations with a higher incidence of cancer would have gone through the "epidemiological transition" (Weindling 1992), while those burdened by infectious disease had not yet gone through that "step."

"Epidemiological transition," whether due to medical advances or to the improvement of nutrition standards (see McKeown 1976, Vogel and Rosenberg 1979), stands as the health counterpart of the demographic transition, and also as an equivalent to the economic "take-off" (Rostow 1960). The notion of an evolutionary take-off is a theoretical elaboration of the quite widespread belief that some countries have already attained prosperity while some lag behind in a similar evolutionary path to modernity.

Even though the "modernization" way prevails as common sense for many and as a solidly established ideology, the

belief in one-way socio-economic evolution has been dismissed since the 1960s. Sociological and economic analyses (e.g. Amin 1976, Cardoso and Faletto 1967, Frank 1967, Wallerstein 1974-80) have interpreted the world system of inequities in terms of dependency theory. Rather than a natural state of backwardness, underdevelopment results from a situation of international dependency. The mechanisms of economic dependency and social differentiation are used by some authors to explain the contrast in morbidity patterns at a world level (e.g. Arnold 1988, Minayo et al. 1995, Navarro 1981).

The modernization/dependency arguments are often used to explain the unequal distribution in the production of science in the world. The most widespread views stand within the assumptions of "modernization," and therefore see no place for scientific production in the peripheral countries. Science goes with modernity and that is a propriety of the few "developed," central countries. Secondary arguments reinforce the primary belief: scientific development requires the resources and infrastructure that only developed countries can provide; the few existing scientists coming from the developing countries are either frustrated by the lack of work

conditions in their home countries and do not produce enough original research there, or they migrate to the main research centers located in the developed world, becoming a part of cosmopolitan society rather than the developing world. Since there is no local production, there is no funding for it either, the argument goes, and no new production can grow.

Analysts who take the perspective of dependency theory argue that the scarcity of scientific production in peripheral countries is not a characteristic of backwardness, but an effect of the same mechanisms that cause underdevelopment. Not that scientific creativity is absent from the developing world, but it is either suffocated by research interests defined elsewhere, by economic interests of local elites, by epistemological Eurocentrism of mainstream science, or by a complex interaction of socio-economic and political factors that reproduce the situation of dependency. Debates on the nature of underdeveloped science, science and modernization, dependent science, or third world science, even though less visible in the "centers" of knowledge production, have engaged scholars in "peripheral" settings, from Asia (Goonatilake 1993, Moghadam 1991, Sardar 1988, Shrum and Shevan 1995) to Latin America (Benchimol 1990, 1995, Benchimol and Teixeira 1993, Botelho 1990, Cueto 1989, Fernandes 1987, Ferri and Motoyama 1979, Lopes 1964,

Marques 1989, Morel 1979, Motoyama 1988, Niskier 1970, Paty 1992, Polanco 1985, Sagasti 1971, Schwartzman 1978, 1979, 1981, 1982, Stepan 1976, Valle and Silva 1981, Vessuri 1987) as well as more or less radical analysts from the U.S. and Europe (Bernal 1972, Clark 1985, Cooper 1973, Dedijer 1968, Gaillard 1991, Navarro 1981, Polanyi 1968) and research sponsored by the United Nations (Morazé 1979, Morazé et al. 1980, Pannier 1979, Salomon et al. 1994, Silva 1980).

It is no coincidence that a significant amount of critical literature on dependency comes from, or is inspired by, the experience of Latin America after World War II.³ This is a region where the externally induced obstacles to internal development can be traced clearly. Furthermore, the proximity between the minority of literate and cosmopolitan middle and upper classes who share the social patterns and life-styles of the developed world, and a vast majority of poor population, which endures the burdens of underdevelopment, creates a field for theoretical developments that account for the social and structural dimensions of human agency and existence. This extends to the study of health, within which evolved a radical and theoretically original epidemiology, the so-

³A parallel argument can be made regarding the fact that most current literature on "post-colonialism" comes from and is inspired by the experience of India -- and can hardly be translated into the study of South America.

called Latin American school of social epidemiology (Breihl 1981, Laurell 1976, 1987), today updated to more "syncretic" positions in Brazil (see Almeida Filho 1989a, 1989b, 1990a, 1990b, 1991a, Costa 1990, 1993, Minayo 1995, Physis 1993, Possas 1989, Sabroza et al. 1995) that account for the flexibility of central locations and the constant production of peripheries.⁴

Dependency theory influenced many other aspects of the study of health in Latin America. In a country such as Brazil it is fair to say that the entire medical field is influenced by the notion that, at some level, illness is socially determined. The sophistication of local development in the field of social medicine and the study of infectious diseases was a factor in my selection of that country as a counterpoint to the United States for the study of responses to AIDS and the ensuing knowledge production. In addition to this reason, which will be explored further in the later chapters, Brazil also deserves special attention as one of the countries most affected by the epidemic. The contrasts and similarities

⁴According to epidemiologist Paulo Chagastelles Sabroza (personal communication, 1992), the Brazilian and Venezuelan schools of epidemiology are more moderate than the radical historical materialism schools of Mexico and Ecuador. "Moderation" accounts for the inclusion of the individual level in the determination of the disease, as well as the inclusion of structuralist and Foucauldian notions, traditionally rejected by most orthodox Marxist analysis.

with the epidemiology of the United States and the developed world, and other contrasts and similarities with African epidemiology, along with Brazil's internal contrasts and intertwined politics, make the case of AIDS in this country worthy of detailed study.

Whether under the paradigm of "modernization" or of "dependency," the conventional partition of the world health system in two clearly distinct zones of development and underdevelopment was challenged by the AIDS epidemic. Classified as an incurable infectious disease, or rather as a lethal combination of what used to be treatable infections, AIDS brought to the very core of the developed world an experience of collective distress and helplessness that had long been forgotten, and that, for many, was entirely ignored.

No material or cultural resources could rescue the ills of the radically unknown new illness; more knowledge was needed. In spite of the significant amount of knowledge about AIDS produced since the acknowledgement of the epidemic, much of it in the high-tech area of molecular genetics, our current understanding of AIDS is still loose, insufficient, inadequate, and often the fast pace with which contradictory views are produced make them all

seemingly unreliable. Medicine is still helpless with regard to a cure or to an effective preventive vaccine. Educational prevention is not sufficient for the collective behavioral changes needed to stop the epidemic. Moreover, preventive efforts clash with cultural and political obstacles,⁵ turning the mission of educational workers and agencies into an immense difficulty.

AIDS strikes across class, nation, race, and gender. It affects us globally, as major health agencies have stressed (Earickson 1990, Mann et al. 1992, Panos 1989, 1990, Sabatier 1988, Schopper 1990, WHO 1988c, 1989b, 1989c, 1992, 1994b), and it highlights the contrasts and contradictions of contemporary society, as social scientists and international agencies have documented (e.g. Amat-Roze 1993, Crawford 1994, Farmer et al. 1993, Feldman 1994, Perrow and Guillén 1990, Singer 1994b, WHO 1994b).

Bringing together the developed and the underdeveloped, centers and peripheries, first and third worlds, homogenizing the globe through a shared health problem, the epidemic subverts the partition of the world health system. On the other hand, AIDS intensifies the class, gender, nation, race, and sexual orientation

⁵This includes the AIDS epicenters like New York: regardless of the fact that sexual and drug-related needle sharing account for most HIV infections in the city, safe-sex education for teenagers is repressed, needles cannot be purchased, and safe-injecting educators are arrested.

differences (see Lindenbaum 1992). Simultaneously homogenizing and differentiating, the epidemic mirrors the contemporary world and reverberates throughout its structures.

This correspondence between contemporary world structures and the face of the AIDS pandemic is central to this study, where the main axis of approach to the subject is the social production of knowledge about AIDS, with a specific focus on **biomedical science**.

Self-defined as universal knowledge and claiming to stand above the constraints of local culture, scientific knowledge was exempt from the scrutiny of social sciences until quite recently. However, there has been a wave of theory and enquiry within the energetic field known either as Social Studies of Science (SSS), Sociology of Scientific Knowledge (SSK), Science and Technology Studies (STS or S&TS), or Cultural Study of Science (CSS), depending on the author (e.g. Barber 1990, Barnes 1974, 1982, 1988, Barnes and Shapin 1979, Barnes and Edge 1982, Bloor 1971, 1976, 1983, Brante et al. 1993, Chubin and Restivo 1983, Collins 1982, 1983, 1985, Fuller 1993, Hess 1992, 1995, Hicks and Potter 1991, Jasanoff et al. 1995, Knorr-Cetina and Mulkay 1983, Labinger 1995, Pickerin 1992, Pinch 1992, Restivo 1995, Shapin 1992, Traweek 1993).

Scholars working in these areas have documented for several disciplines what historians of medicine and medical anthropologists (e.g. Arnold 1993, Good 1994, Wright and Treacher 1982) have been saying all along for medical knowledge: that it is socially produced and historically situated. Philosophy-oriented scientists (e.g. Fleck 1935, Keller 1995, Lewontin 1992, Reif 1961) have also approached the issue of the social construction of scientific knowledge, sometimes in their own "native" terms (Latour 1990), relativizing science's claims for absolute universalism. Scientists, too, have used the tools of social and historical analysis (Haraway 1991, Keller 1983, 1985, Labinger 1995, Löwy 1989, 1990, 1991, 1995). Ludwick Fleck's work on syphilis and the Wasserman reaction (1935) is a paradigmatic case around which many of the social studies of science developed, namely those involving the bio-sciences (e.g. Harwood 1986, Freudenthal and Löwy 1988, Löwy n.d.).

Opening the "black-boxes" of science (Latour 1987, Pinch 1992) and exposing through analysis the "guts" of the social process of constructing scientific knowledge may have disturbing relativist effects; Latour recommended that such meta-knowledge should not be left accessible to the practitioners of science. Their activity seems incompatible with the relativism that stems from the analyses. Not necessarily a consequence of the analysis, relativism

lingers around it, as researchers in social studies of science have debated (e.g. Collins 1995, Daly 1990, 1991, Haraway 1991, Labinger 1995 and replies, Latour 1990, Oldroyd 1990, Restivo 1995, Turnbull 1991).

The problems of relativism are quite familiar to the practitioners of anthropology, who are often placed in border-line situations where their own ethics and beliefs may be challenged by the ethics and beliefs of the people they are involved with. The experience is pushed to the limits in medical anthropology, where issues of life-and-death are at stake. Knowledge about AIDS only re-enacted those problems with stronger tones, as it will be examined again and again throughout this text.

The process of making science and producing knowledge about AIDS is subject to constant public scrutiny, negotiation, debates, and close reporting by the media. Science's fragile, limited, and inconclusive knowledge about AIDS is exposed bare and raw, yet it is nonetheless the basis for public policy, medical decisions and individual choices that have a close and direct impact on matters of death or survival, treatment, quality of life, sexuality, fear, prejudice, support, prevention, political intervention, and international action. The fact that absolute decisions depend on disproportionally relative and temporary certainties only increases the distresses of relativism. For that reason, opening the "Pandora's box"

(see Gilbert and Mulkay 1984) of knowledge about AIDS is an additional challenge.

That science on AIDS is so closely scrutinized both simplifies and complicates our task: on the one hand, there is a considerable volume of documentation available on the hypotheses, research methods, debates and processes of achieving consensus. Polemics are covered by the media and registered in popular books, and scientists are available for public debate. On the other hand, public scrutiny increases the number of factors reverberating in the final consensual results; public discussion is not just the poorly tolerated "ghost in the machine" (Bourdieu 1975:39) whose existence is acknowledged, yet not incorporated, in other areas of knowledge. Scientists involved in AIDS research cannot ignore or alienate from the public discussions and social scrutiny on their topic; these social forces directly influence research through pressure and funding.

The history of accomplishments and failures in our collective attempts to understand and act upon AIDS cannot escape from being also one more account of distress and frustration. In spite of the many achievements in the past ten years, medical and social ability to manage AIDS are

still far from the self-confidence that characterized modern medicine at the eve of this epidemic.

In the United States, the failures of medicine to efficiently address the epidemic were attributed by critics and activists, from the beginning, to lack of funding, of political interest, of basic scientific research, clinical understanding, or social understanding (e.g. Crimp 1990, Feinberg 1994, Kramer 1989, McKenzie 1991, Nelkin et al. 1991). However, more research, money, awareness, and even government commitment did not resolve the problem. The efforts put into AIDS research by different social partners, from grass-roots activism to top-level sponsored research, have been responsible for dramatic changes in a microscopic or micro-social level, but they have not led to a satisfactory understanding of the larger picture or a significant change in the patterns of the epidemic.

As with cancer, we are left with unsatisfying pieces of knowledge and a disturbing inability to act upon a infectious disease whose viral agent, HIV (**Human Immunodeficiency Virus**), is fully described and genetically mapped with state-of-the-art microscopic technology, but whose role in the development of AIDS-related infections is poorly understood. Does HIV infection require co-factors in order to develop full-blown AIDS? If yes, are those the mycoplasmas that Luc Montagnier so often brought to discussion, or are they something else? Is there a non-

active state of infection? Can one have a latent infection forever? Can the HIV positive serostatus be reversed? Why do some get infected and others don't? Why do some people remain infected as asymptomatic for so many years, while others collapse with secondary infections and die rapidly? What happens to the immune system cells other than the T-lymphocytes when there is HIV infection? What are we to think about some microbiologists' claims that HIV has no relevance at all in the development of AIDS? Hundreds of such questions linger around those affected by the disease or involved on its research, showing how little our certainties are. In regard to treatments, consensual knowledge changes constantly. The drug of choice in one year is replaced by a different one in the next year; the ideal form of administration changes frequently, and even the "alternative" drugs of election change all the time.

Multilayered and multivocal, impossible to limit to a linear narrative, the history of responses to AIDS is one of various meanings attached to a common referent, which is also a new fact of health, life, and suffering. Science unified this crisis as a novel field of research in the biomedical sciences and as a challenge for epidemiologists, virologists, immunologists, physicians, and all health professions. At the same time it is a new field of research and a medical challenge, AIDS is a multiple-faced tragedy and a site for action, a new and devastating experience of

grief and loss, individual and collective; it is the scapegoat for the exercise of conservative hatred; it is a field for social intervention in developing countries and international aid; for social scientists, it is also the grand challenge of a "total social fact" whose whole we try to grasp while we keep producing bits and pieces of partial knowledge.

The voluminous literature already produced on AIDS includes a number of specialized scientific journals, like **AIDS**, the **Journal of Acquired Immune Deficiency Syndromes**, or **AIDS Research and Human Retroviruses**, plus endless articles and special issues in mainstream scientific and medical journals, like the **New England Journal of Medicine**, the **Journal of the American Medical Association (JAMA)**, **Annals of Internal Medicine**, **Lancet**, **British Medical Journal**, **Reviews on Infectious Diseases**, **Journal of Infectious Diseases**, **Science**, **Scientific American**, **Science et Vie**, **Social Science & Medicine**. In addition to the medical, psychological and social work textbooks, and the policy reports and recommendations, in the United States alone there is an extensive number of books on self-help, survival, life enhancing, activism, and social analysis; there are popular magazines, either from the gay press or specifically for an HIV positive clientele, like **POZ**; treatment newsletters, like San Francisco's **AIDS Treatment News** to New York's **Treatment News**, **TAG's** newsletter, and

the handouts of **ACT UP Treatment and Data Committee**; plus a diversity of other materials like videos, films, and books addressing social, political and human aspects of AIDS in documentary or fictional forms. With varying emphases, the mainstream media have covered the epidemic opening special columns and assigning science journalists to AIDS (see Burkett 1995, Garret 1993, Kinsella 1989).

From within the epidemic, a new genre of literature has given voice to those who live personally the burden of this new and lethal disease which painfully exposes the limitations of contemporary medicine (Arenas 1993, Callen 1987, 1990, Crimp 1987, Daniel 1989, Feinberg 1994, Guibert 1990, 1991, 1992, Kramer 1989, Monette 1988, Schecter 1990, Watney 1994, Wojnarowicz 1991). Such expressions of grief extend beyond real-life literary chronicles into a number of other artistic media, with several projects in the performative and fine arts specifically dedicated to AIDS, like **Gran Fury**, Keith Haring's works, and the **Day Without Art** as a testimony to the devastating effects of the epidemic among the artistic community.

Development agencies have produced special reports on the impact of the epidemic in developing countries (Fleming et al. 1988, Mann et al. 1988, Mann et al. 1992, PAHO 1989, Panos 1989, 1990, Sabatier 1988, WHO 1988b, 1989b, 1994b). Developing countries contribute to the international scene not just as recipients of foreign aid but by bringing

knowledge from their own experience with AIDS, health, prevention strategies and social agendas, as is stated in virtually every issue of newsletters like **AIDS Action, Exchanges**, or **Boletim ABIA**. International agencies presented their synthesis of the diversity of experiences under the "global action" agenda (Mann et al. 1992, WHO 1992). New media were adopted to handle the rapidly expanding information on AIDS: CD-Rom, fax, on-line conferences, e-mail and other computer network devices, like the electronic databases AIDSline and SIDSA, a number of Bulletin Board Systems on AIDS, and, more recently, the sites of AIDS agencies on the World Wide Web. Interactions between these different media multiply the amount of circulating messages, making it hard to manage the existing information and impossible to reduce AIDS to a single structured account.

Anthropologists and other social scientists have contributed to the narratives on AIDS in various ways: with accounts from the midst of the epidemic (Bolton 1989, Feldman and Johnson 1986, Horton 1989, Horton and Aggleton 1989, Pollak 1988, Pollak et al. 1986, Watney 1990, 1994); with prevention-related or assistance-related research (e.g. Bolton and Singer 1992, Bowser 1994, Davies et al. 1993, Gorman 1986, Gupta and Weiss 1993, Hahn 1991, Koester 1994, Magaña 1991, Pivnick 1993, Pollack 1994, Schiller 1993, Sobo 1993); compiling the challenges of producing

theory and testimony in the midst of the crisis (Aggleton, Hart and Davies 1989, 1991, Aggleton, Davies and Hart 1990, 1992, 1993, Berridge and Strong 1991, 1993, Carter and Watney 1989, Farmer, Lindenbaum and Good 1993, Fee and Fox 1988, 1992, Graubard 1990, Herdt and Lindenbaum 1992, Loyola 1994, Paiva 1992, Parker, Bastos et al. 1994, Thiandiére 1992); studying responses to AIDS among specific social groups like gay men (Bayer 1985, Bolton 1995, Carrier and Magaña 1991, Davies et al. 1993, Gorman 1991, Katarbe and Lang 1986, Herdt et al. 1990, 1991, Murray 1990, Pollak 1988, Pollak and Schiltz 1987), drug users (Carlson et al. 1994, Clatts et al. 1994, Connors 1992, Friedman et al. 1989, Goldsmith and Friedman 1991, Kane 1991, Neaigus 1994, Neaigus et al. 1990, Ratner 1993, Siegel 1988, Stall and Wiley 1988, Sterk-Elifson 1993), women (Ankrah et al. 1994, Clatts 1993, Goldstein 1994, Gupta and Weiss 1993, Henderson 1991, Schoepf 1992a, Sobo 1993, Tuchel and Feldman 1993, Ward 1993, Worth 1990), or contextualizing the epidemic in particular socio-cultural settings like Africa (Caldwell et al. 1992, C. Good 1995, Packard and Epstein 1991, Schoepf 1991, 1992a, 1992b), Haiti (Farmer 1992), Brazil (Parker 1987, 1988, 1991a, 1992, 1994a), and the contrasting U.S. or European settings (Bolton 1992, Bowser 1994, Clatts 1991, Lewis and Watters 1989, Lindenbaum et al. 1993, Quimby 1992, Singer 1994b, Singer et al. 1994, Sterk 1993); developing the social

study of sexuality (Bolton 1992, Cagnon 1988, 1990, Carrier and Magaña 1992, Davies and Coxon 1990, Parker 1988, 1992); analyzing representations and cultural aspects associated with risk and stigma (Crawford 1994, Farmer 1994, Frankenberg 1994, Gilman 1988, Goldin 1994, Héritier-Augé 1992, Pierret 1992, Schiller et al. 1994, Threichler 1988, 1992); questioning methodological and theoretical aspects (Abramson 1992, Lindenbaum 1992, Pollak et al. 1992, Threichler 1991); or creating social commentary (Bateson and Goldsby 1988, Scheper-Hughes 1994).

Anthropological contributions have not altered the fragmented nature of knowledge about AIDS: the involvement of anthropologists with the epidemic often locates them within the local narratives produced by each experience of it, generating a diversity of perspectives that may not be exempt from antagonist confrontations, as those who witnessed the 1992 AAA panel on AIDS may remember (see AAA 1993, Singer 1994a, Scheper-Hughes 1994), or the polemics that heated **Social Science and Medicine** readers after the publication of an article with racist contents (see Leslie 1990).

Rather than exhibiting the old disciplinary trademarks of monographic synthesis and holistic overview on the studied topic, anthropological works on AIDS are as dissonant and fragmented as our knowledge about this epidemic. In that, they portray the state of the

discipline. Would a further level of synthesis, in methods and in theory, be desirable from any perspective? During the research, I sensed as if some of the AIDS-related social phenomena **demand**ed a higher level of synthesis, one that would have to involve exploratory methodology and theoretical development. That was the case of the multi-tracked International Conferences on AIDS (annual until 1994, bi-annual since then), of WHO's multi-departmental AIDS Programme, and of the action of agencies like the **Global AIDS Policies Coalition** (see chapter 3). These phenomena intertwine science, clinical management, activism, politics, policies, issues of development, and social analysis; their format seems to suit the old holistic tradition of the discipline, now with a "macroanthropological" flavor.

Inspired by the pre-existing macroeconomy and macrosociology, a **macroanthropology** (Hannerz 1988), involving the study of global issues and taking its worldly field as an interconnected web of networks, could provide the frame to address the universe of AIDS in a synthetic manner. The interconnected social networks which handle the epidemic might be approached as a community that has some ritual physical appearance (as the yearly mega-conferences) and occupies the entire world: a community of contradictions and dissonances, much in a post-modern presentation.

But this work does not aspire to be a collage of contradictory narratives portraying the world of AIDS as the ultimate post-modern issue, with its scattered horizon of dissonant voices at the verge of turning into a noisy and pointless cacophony, or splitting into an endless number of irreducible self-sustained truths.

Such a "post-modern" scenario is not the goal of this analysis, but serves to provide the setting to inquiry into the unfinished project of modernity and enlightenment, **science** (Habermas 1981, 1983). For AIDS as for other subjects, it has been demonstrated that the "enlightened" project of science is pursued in less "enlightened" ways, which include private interests from laboratories, academic and political institutions, as well as competition within the scientists' star-system, homophobic and xenophobic prejudice, and often sloppy research (see Burkett 1995, Camargo 1994, Moraes and Carrara 1985a, 1985b, Center for Social Research 1991, Nussbaum 1990, Patton 1985, 1990, Threichler 1987, 1988, Root-Bernstein 1993). Nonetheless, science is the unifying force that defines the ills experienced by a woman in Haiti, a gay man in Manhattan, or a child in Zaire as one and the same, that is to say, HIV infection, or AIDS. Likewise, a laboratory assistant preparing a PCR test, a statistician modeling projections on HIV for the next decade, and an outreach social worker interviewing prostitutes and housewives share the same

topic of research, unified by science on AIDS. Moreover, a new and transnational identity is defined by the "AIDS doctor," crossing over different specialties, locations, and background. Added to this new professional area, there are also the generic "AIDS specialists," those who compose the "AIDS establishment," which, as diverse as it may be, is still defined under the unifying criteria legated by science.

In the field of AIDS as elsewhere, science is the product of human activity and a complex mirror of social structures, which are an appropriate subject for the sociology and anthropology of knowledge (e.g. Crick 1982, Elias 1971, Kulick 1983). Defined as attempts to understand the relationship between specialized bodies of knowledge and the cultural and social contexts in which they are produced (e.g. Mulkay 1979:1), the anthropology and sociology of knowledge have traditionally left science out of their scope. This has been attributed to the particular epistemological status of scientific knowledge (see Mulkay 1979:2,26), the same which grants legitimacy to sociology and anthropology. In Bourdieu's analysis, the difficulty of a sociology of science (his use of sociology being an extended one, for the social sciences in general) lies in the fact that "the sociologist has a stake in the game he undertakes to describe" (Bourdieu 1975:40). In fact, it is the double stake of the scientificity of sociology in

general and of the particular form of sociology employed (Bourdieu 1975:40).

The equivalent debate has been addressed by medical anthropologists, who have discussed whether biomedicine should be studied as just one more ethnomedicine, the one produced by western modern cultures, or as a special and legitimate scientific knowledge free of cultural constraints. The debate has been settled with mature studies in the anthropology of biomedicine that do not slip into relativism (e.g. Good 1994, M. Good 1995, Greenwood et al. 1988, Hahn and Gaynes 1985, Lindenbaum and Lock 1993, Lock and Gordon 1988, Stein 1990).

Avoiding epistemological depths and leaving relativism at bay, most scholars involved in the sociology of science have focused on the "external" sociological aspects of science, rather than its actual content. In the U.S., this position has been attributed to the influence of Robert Merton (1973). In Latour's words, "recognition, quotations, competition, budgets, were what impassioned American sociologists [studying science]" (1983:204-205). The actual cognitive "internal" result of such activity, that is, scientific knowledge, was left to humanistic disciplines like philosophy, epistemology, and, occasionally, to the history of science. Merton followed Talcott Parson's version of Weberian theory, even though Weber's sociology of religion (1963) had set the guidelines for a creative

social exploration of the contents of knowledge that could account for science as well. Other guidelines are located in the work of Durkheim (1912) and Marx (1973), or Mannheim (1936), and, more recently, the constructivist perspective of Berger and Luckmann (1966). Had they been willing to pursue the study of scientific knowledge as a social production, contemporary social scientists had a number of references to follow.

Marx's philosophy demonstrates that systems of ideas are socially determined, even though the status of scientific theories within a multitude of other ideological systems of knowledge remains less explicit. Throughout the twentieth century, Marxist authors and politicians evoked the distinction between proletarian and bourgeois science, in a way similar to the treatment of art in the early years of Soviet Union -- without, however, exploring much of its contents. Marxist theorists, from Lenin to Althusser, differentiated "truthful" scientific knowledge from "untruthful" ideological knowledge; while this distinction matters for social knowledge, it hardly works in domains like biology, physics or mathematics (for the rare attempts see Baracca and Rossi 1976, Barletta 1978, Levidow 1986, and the classical Hessen 1931).

Unlike the "ideology=false representation" supported by most Marxist theorists, Mannheim's ideology/utopia duality established creative principles for a future

sociology of knowledge, which was developed only a few decades later.

A further stem of sociology of knowledge comes from the rationalist Durkheimian tradition. In the **Elementary Forms of Religious Life**, Durkheim (1912) described religion as the apotheosis of society and showed how this primitive form of thinking was the basis from which others, including science, were derived. Knowledge was seen as fundamentally shaped by social categories which preceded logical categories, as stated in the founding essay on primitive classifications (Durkheim and Mauss 1963). This tradition, which influenced most francophone and francophile social science, relied on faulty philosophical arguments (see Crapanzano 1995, Mulkay 1972), and did not provide a firm basis for the development of a sociology of knowledge which could address the contents of science.

Another anthropological perspective addressed science in relation to magic. Evolutionists considered magic as a form of primitive science that, permeated by non-rational beliefs, established relationships between facts (Frazer 1900, Tylor 1870). Functionalists demonstrated that magic, science and religion were parallel rational systems of action and thought which related humans to nature (Malinowsky 1948). Structuralists elaborated distinctions between the internal logic of the two systems (Levi-Strauss 1962a) and showed how the relations between humans and the

natural world expressed in totemic religions are actually about social relations among humans (Levi-Strauss 1962b).

In spite of these preliminary efforts to account for science within the scope of the sociology of knowledge, only in the 1970s was there a full attempt for a sociological exploration of scientific knowledge. Pierre Bourdieu's analysis of the scientific "field" (1975) helped to break the ground by eliminating the divide between externalists and internalists. In his words,

an authentic science of science cannot be constituted unless it radically challenges the abstract opposition ... between immanent or internal analysis, regarded as the province of the epistemologist, which recreates the logic by which science creates its specific problems, and external analysis, which relates those problems to the social conditions of their appearance. (1975:22)

A few years earlier, British sociologist Michael Mulkay (1972) had approached the question by discussing the **social** conditions for **paradigm shifts** (Kuhn 1962) or **scientific revolutions**, which epistemologist Thomas Kuhn had presented as a product of internal proprieties of the scientific process or of the pure interplay of ideas. Situating the analysis within the "problem-networks" that constitute scientific communities, Mulkay rightly asked that the next step of inquiry should focus on the impact of

social factors outside scientific networks in shaping the contents of science.

Also, the immense influence of Foucault's **Archaeology of Knowledge** (1969) in the 1970s' intellectual life provided know-how and a background reference for denser explorations of the social and political character of knowledge constructs.

Whether influenced directly by these works or by a broader historical moment and shared *zeitgeist*, a few sociologists and anthropologists in the late seventies and eighties broke the former "taboo" and directly examined the production of scientific knowledge.⁶ The endeavor was pursued on different fronts. The so-called new sociology of knowledge combined ethnographies of the laboratory, discourse analysis and detailed accounts of the process of achieving consensus in science to produce a thick description of the micro-social processes through which the

⁶Coinciding with the upheaval of science studies, and certainly for parallel reasons, anthropology experienced its own moment of introspective reflection (e.g. Marcus and Fischer 1986). Following the post-colonial proximity between ethnographer and ethnographed and the disturbing questions about the accuracy of what used to be taken-for-granted ethnographic testimony, focusing on the character of anthropologists-as-author, this current briefly disturbed the discipline leaving positivists and realists threatened by the specter of hermeneutic conversion and the loss of scientific virtue. The movement helped to relativize the authority of ethnographic knowledge by analyzing the social conditions of its production; in that respect, it should be seen in association with efforts to analyze the social production of natural sciences and technology.

contents of science are produced and the identities of scientists are defined (Collins 1985, Gilbert and Mulkay 1984, Knorr-Cetina 1981, Latour and Woolgar 1979, Lynch 1985, Traweek 1988). One of the central streams of this current, but not the only one, coincides with the British non-Mertonian school of sociology of science, and its Edinburgh-Bath-Manchester tripod.⁷

Another important source for the social study of science stems from the feminist literature and its critical exam of hegemonic discourses and practices. Feminist authors challenged the male-biased authority of scientific models in a number of ways (Keller 1985, Haraway 1989, Harding 1986, 1993, Harding and O'Barr 1987, Jacobus et al. 1990, McNeill and Franklin 1991, Martin 1987). This approach became the main point of reference and inspiration for the social studies of science in the United States (see Franklin 1995b), one that few philosophers of science acknowledge as a stem of transformation (see Rouse 1987:xi), and yet is the favorite target for the "realist/rationalist" opponents of the sociological analysis of science (Brown 1989, Gross and Levitt 1994).

Having a different yet close social motivation, the analyses questioning the scientific basis of racism also

⁷These are the sites where programs, courses or publications on the new sociology of science most strongly developed: Bath with Harry Collins, Edinburgh with David Bloor and Barry Barnes, Manchester with Michael Mulkay.

constitute a background to challenge the scientific discourse, its models and deriving public policies, as Reid (1975) for the sickle-cell case in the United States. Far from buried as an historical reference, "scientific" racism makes frequent comebacks, as the recent case of the **Bell Curve** shows.

The social study of science is complemented by other exploratory approaches to scientific practices and productions that come from diverse socio-cultural contexts (Rubinstein et al. 1984, Turnbull et al. 1989).

Today, social studies of science gravitate around aspects of technoscience and technoculture (Center for Social Research 1991, Marcus 1995, Penley and Ross 1991), and include topics from cyberculture (Escobar 1994) and artificial intelligence (Forsythe 1993) to artificial life and reproduction (Edwards et al. 1993, Franklin 1995a, Ginsburg and Rapp 1995, Longino 1995, Rapp 1993, Strathern 1992), as well as explorations of contemporary medical knowledge such as genetics (Heath and Rabinow 1993, Hilgartner 1995, Rapp 1994), the formulation of questions (Clarke and Fujimura 1992, Fujimura 1987, 1988), medical technology (Dumit 1995, Rabinow 1993a, 1993b) the immune system (Haraway 1989, Martin 1992, 1993, 1994) and AIDS (Epstein 1991, Erni 1994, Horton 1989).

The enquiry into the social production of knowledge is haunted by the implications of relativism (see Feyerabend

1993, Laudan 1990), a theme that has been addressed in a variety of ways by the sociology of scientific knowledge, or SSK (e.g. Daly 1990, 1991, Haraway 1991, Labinger 1995 and replies, Latour 1990, Oldroyd 1990, Restivo 1995, Turnbull 1989, 1990, 1991). Suspicious of the anti-science attitude which radical relativism may generate, some scientists and rationalist philosophers rejected and dismissed the endeavor of Science & Technology Studies (e.g. Brown 1989, reviewed by Shapin 1989, and Gross and Levitt 1994, reviewed by Franklin 1995b; see also Hess 1995). Social analysts are not forgiven by "hard-line realists" for daring to cross the line which Merton so strictly respected and "intrude" on the contents of science. The backlash against SSK (Restivo 1995), or "STS-bashing" (Hess 1995) increases the challenge for social researchers in this unsettled field. This is even more so when the subject is medical knowledge, upon which matters of life and death depend so tightly, and which, unlike nuclear physics or biochemistry, researchers face on a personal and daily basis.

This difficulty is intensified in the study of AIDS, where, in addition to the problems of relativism, we face a kind of knowledge grounded in multiple and contradictory social contexts and folded in social mechanisms that rapidly scrutinize the process and provide it with feedback. Overall knowledge about AIDS reverberates that

multi-layered, multicomponent process, and gives us clues about contemporary society while reminding us of the social character of scientific production. In this study I will overview some of the streams that compose knowledge about AIDS, from social knowledge, activists' knowledge and public awareness, to academic production and clinical experience. The process involves a range of social actors, from scientists and physicians to activists, public officers, non-governmental organizations and international agencies. I will describe the actors and the social process of knowledge making with a particular focus on its social negotiation (Chubin and Restivo 1983) and the final outcome in fields like prevention, treatment, epidemiology, and immunology.

As with cancer, social expectations about better, more efficient and comprehensive medical knowledge about AIDS in America were consonant with the desire for individual and collective rescue from the ills of the disease. The development of patient-based activism helped to raise the hopes for a solution and a cure. While this new social movement increased the gap between what was demanded from scientists and what they produced on AIDS, it also helped developing new channels of interaction between the

different partners implied in the several fronts of response to the epidemic. Some of those new channels resulted in innovative forms of producing knowledge as well as new tools for intervention in this health crisis. Previously inconceivable partnerships between scientists and activists, doctors and patients, the gay-inspired social movement and the medical establishment, or pharmaceutical laboratories and community organizations, and their impact in the production of new forms of knowledge, will be analyzed in chapter 2.

Another unusual partnership, sponsored by international agencies, brought together the First and Third Worlds, developed and developing nations, central and peripheral settings. Institutionally-sponsored global action helped raise expectations of major change (see chapter 3). AIDS officers from WHO even mentioned the "health revolution" created by the responses to AIDS, which expanded the scope of action beyond the strict sphere of biomedicine and into its social, economic and political dimensions. This notion helped mobilize the energies of social movements around the world, and transferred into the field of AIDS a kind of political activism that had developed around other social issues, such as the fight against military dictatorships in Latin America, or community organizing, or promoting outreach to low-income populations.

This "globalizing" move resulted in the creation of an arena which united the ultra-developed and the underdeveloped, short-circuiting the partition of the world and bringing together the high-tech frontier of research and the "wastelands" of infectious diseases. This new junction raises interesting questions: what should be the impact of this move in the ultimate universalist project of science? Is this "global" scenario the setting for the "truly universal culture" that some authors (e.g. Amin 1989:136) envisage as replacing Eurocentrism?

Social scientists interested in the production of knowledge have long noticed the fermenting power of disciplinary migrations and encounters between unusual partners (Löwy 1992:371, Mulkay 1972). Discussing the need to overcome the limitations of contemporary knowledge about AIDS, Horton and Aggleton (1989) prescribed the crossover between social and medical disciplines. A similar argument could be made about the encounters, forced by AIDS, between high-tech and peripheral medicine. In Brazil, the close proximity in which both worlds coexist has important results in a fertile social medical thought. Would there be anything equivalent to that fermenting power at a wider, global level?

The ground for a scientific revolution, a leap in knowledge worthy of being called revolutionary, gained definition. That seemed to be implied in the hopes for a

major achievement like a cure for AIDS, and there were the conditions for it. From a science observation perspective, the more it appeared that results of AIDS research led to frustrating dead-ends, the more it seemed that a real change was needed, a leap in the health sciences along the lines of a Kuhnian "paradigm shift" (Kuhn 1962), in its **normative** rather than in its **descriptive** reading.⁸ If encounters between different partners could lead to a shift in knowledge models, there seemed to be the occasion for one.

The change could take place in the path-breaking field of immunology, in the dormant area of infectious disease, in the intersection between them, or in the "softer" field of epidemiology, the borderline between the health and social sciences. Knowledge that was available, and was being produced at an impressive pace, like molecular genetics, did not seem to be of significant help to those affected by the epidemic, or to alter its course.

When AIDS was described as an infectious disease caused by a virus in 1984 it seemed likely that a cure would follow. However, no equivalent breakthrough in terms of treatment came from the laboratories. HIV was more complex than the models used to frame it could account for. Most basic research was dedicated to the genetic details of

⁸For an analysis of Kühn's ambivalence, see Bourdieu 1975:38.

the virus; research on the poorly understood immune system was left behind for the more popular and easy rewarding field of molecular biology. Therapeutic research was oriented towards the finding and production of anti-virals with specific targets, namely directed at reverse transcriptase. The limited action of antivirals tested through the years should have signaled the need for a revision of the lines of research used in basic science, yet this revision did not come from the advanced laboratories, nor even from the public agencies. As we will see in chapter 2, it mostly came from the affected communities. Mainstream research on AIDS, both on basic science and drug development, followed the patterns of "normal science" (Kuhn 1962), reproducing the basic framework of germ theory by pursuing HIV as the one and only lethal enemy whose annihilation by antiviral drugs or vaccines should be the key to resolve the problem of AIDS.

With a closer look at the process, we can argue that the focus on HIV was itself the social product of a historical context whose variables we know. WHO states how fortunate it was that humanity had just learned about human retroviruses on the eve of the AIDS epidemic. As analysts of science, we may invert the terms of the statement: because there was an open field of focus on cancer-causing viruses, because the discovery of the first human retrovirus, HTLV, was so recent, and HTLV was such a high-

priced significant without significate, if not a sign without referent, it was almost necessary that human retroviruses took the spotlight in the blame for AIDS. Even if there were many other ways at looking at the problem, like trying to understand more thoroughly the human immune system.

In the upcoming chapters, I will explore the impact of responses to AIDS in medical models as well as in other related disciplines and health promotion. Since the pandemic has mobilized "global action" and brought together expertise and experience, laboratory and community action, overdevelopment and underdevelopment, we may ask whether the new partnerships, actual and virtual, have produced a significant shift in medical knowledge.

Outside the strictly biological sciences, as it refers to global policies, a significant shift in knowledge took place: the inclusion of social variables in the understanding of the disease, and the understanding that its "eradication" would have to involve profound social changes in macro and micro power relations (see chapter 3). Further evidence of change is apparent in the area of organization of knowledge, with the growing trend of interdisciplinary settings and transdisciplinary productions (e.g. Mann et al. 1992, National Research Council 1989).

The "softer" discipline of epidemiology was the site of some logical inconsistencies in the study of AIDS (see

chapter 3). The epidemic was framed around a number of variables relevant to the developed countries, stressing the risk of social groups defined in terms of individual characteristics, like homosexuality and drug use. In the developing world, where the explanation of illness accounted for social variables like poverty, deprivation, labor migrations, or explosive urbanization, AIDS might have been framed according to those variables (e.g. Baldo and Cabral 1991, Packard and Epstein 1991, Sabroza personal communication). Yet, evidence from the developing world was not used for further theoretical or methodological developments in the epidemiology of AIDS worldwide. Variations in the epidemic patterns in Africa, for instance, were "domesticated" by the construction of a idiosyncratic, heterosexual-defined, "African" pattern II (see chapter 3).

It remains to analyze whether there were any debates and confrontations of models in human biology and medicine. Did humanity go beyond a narrow understanding of the germ theory and the high tech mystification of molecular genetics that seem to dominate today's human biology and, subsequently, current medical action upon AIDS? Which "more universal" social construction can or could replace a readily deconstructible social construction? And which actors could be involved in it?

These questions will be pursued by approaching the center-periphery interactions in the field of science.

After describing how encounters between scientists and community organizations were the locus of innovation (chapter 2), I will explore the possibilities of another potential, transnational partnership: the one between front runners in medical research, such as elite laboratories engaged in microbiology and cancer research, and experts on local knowledge who have all along been involved with infectious disease, such as specialists in tropical medicine in developing countries. The core/periphery, or First/Third world, developed/developing opposition, rather than the more experimented analytical categories like gender, class or race, will be our key social variable.

Addressing this question from a social science perspective assumes a continuous implicit dialogue with two sets of literature, besides the specific literature on AIDS: the open-ended field that includes dependency, world-systems, globalization and post-colonialism; and the current discussions on the social construction of scientific knowledge, informed by a perspective from one particular periphery within the world system -- contemporary Brazil. Brazilian science and intellectual production, from tropical medicine and epidemiology to social sciences and AIDS activism, rather than just a

subject/object of anthropological analysis, will be the partners and interlocutors of this approach, as well as its source and reference.

Chapter 2

**POLITICS AND THE CONSTRUCTION OF KNOWLEDGE:
AIDS ACTIVISM AS A NEW SOCIAL MOVEMENT.**

The sense that AIDS is not just like any other disease is present in most commentary on the epidemic. AIDS is defined as **different** and **unique**: more stigmatized, less treatable, more dramatized, more funded, less funded, more politicized, glamorized, feared, made morbid and scary, a cause for panic, global panic itself, and a motive for global action (see Altman 1987, Bolton 1989, Burkett 1995, Carter and Watney 1989, Crimp 1987, 1990, Daniel and Parker 1993, Feldman 1994, Gomez 1992, Kramer 1989, Mann et al. 1992, Nussbaum 1990, O'Neill 1990, Panem 1988, Pierret 1992, Pollak 1992, Scheper-Hughes 1994, Shilts 1987, Sontag 1989, Watney 1994, WHO 1985b, 1993c, 1994a). In addition to its already peculiar biology and complex medical development, AIDS is overloaded with politics, social commentary, business, spectacle and public scrutiny.

This chapter will analyze the politicization of AIDS as one of its central distinctive features. Before examining the global aspects of the epidemic (chapter 3) and analyze the close intertwining of medical, social, and political variables in the field setting of Rio de Janeiro, Brazil (chapters 4-6), we should discuss the first and most

vigorous social movement generated in response to AIDS. This movement grew among urban gay communities in North America and had an impact on several of the AIDS fronts: on scientific research, therapeutic drug development, local politics, global policies, and on the several overseas locations that faced the epidemic a few years later.

Because every setting is historically unique, with an idiosyncratic combination of particular health problems and social configurations, each local response to the pandemic is an original combination of international elements and local characteristics. The U.S. gay-based AIDS activism was one of those international elements; directly or indirectly, it influenced the responses to AIDS throughout the world, whether local gay communities existed or not. For that reason, before we analyze the efforts for global action and the particular case of Brazil, we should examine in more detail the U.S. social movement of AIDS activism.

AIDS was not the first epidemic in history to trigger social response (see Risse 1988, Rosenberg 1989). From leprosy (Gilman 1988) and bubonic plague (Slack 1985) in the middle ages, to cholera (Morris 1976, Rosenberg 1962), syphilis (Brandt 1987), the Spanish Influenza (Crosby 1976) yellow fever and smallpox (Carvalho 1987), epidemic disease had significant political consequences in more than one time and location, and its history is imbricated in the history of humankind (Dubos 1965, Garrett 1994, McNeil

1976, Sigerist 1943). Nor was AIDS the first disease generating patient groups; people with diabetes, high blood pressure, cancer, and a number of rare diseases (see Von Giziky 1987), have sporadically formed their own support or advocacy associations. Most vocal of all the health-related social movements, the 1970s feminist groups, such as the Boston Women's Health Collective, challenged the established official medicine. they accused it of being too patriarchal and patronizing towards women's bodies and health. Resisting doctors' pre-determined and biased control, women created channels and networks to develop their own knowledge on health and the body (Boston Women's 1973, Ehrenreich 1973, 1978). They indirectly paved the ways for what in the future would be AIDS activism (Nussbaum 1990:108).

Yet, the level of politicization in the patient-based activism that grew in the fight against AIDS was unprecedented. The social context of the epidemic was also unique. Its early identification as a gay disease (whether this is an absolute statistical statement or a contingent social construction) defined the setting for the emergence of a new social movement that would influence responses to AIDS throughout the entire world.

The first indication of something new in matters of life-and-death in America was printed in the **Morbidity and Mortality Weekly Report** (CDC 1981a, CDC 1981b), a bulletin

that provides epidemiological updates and general surveillance on disease trends around the world, published by the U.S. Centers for Disease Control (CDCs) in Atlanta, Georgia. Medical doctors Michael Gottlieb in Los Angeles, Paul Volberding in San Francisco, and Alvin Friedman-Kien in New York had all been intrigued by the occurrence of rare diseases among their patients, who also happened to be young, otherwise healthy, and gay. These young men were breaking down with **Pneumocystis Cariini** pneumonia in the wards of UCLA's hospital and consulting NYU's dermatologist Dr. Friedman-Kien with what seemed to be a dreadful new version of the previously rare **Kaposi sarcoma**.⁹ To publish this information about new illnesses in peer-review journals like the **New England Journal of Medicine**, though more prestigious, might have taken too long. **MMWR** was the most efficient way to spread the news (Shilts 1987:66-67). Later in the same year, several other independent findings¹⁰ mentioned the prevalence of irregular health situations among young homosexuals (Panem 1988:160).

⁹Laurie Garrett notes that even though Dr. Friedman-Kien took the credit for reporting Kaposi sarcoma, it was noticed for the very first time in the context of AIDS in the University of California at San Francisco Medical School.

¹⁰Gottlieb et al. **MMWR** 30:250-252; Friedman-Kien et al. **MMWR** 30:305-308; Gottlieb et al **N. Engl. J. Med.** 305:1423-1431; Siegel et al. **N. Engl. J. Med.** 306:1439-1444; Masur et al. **N. Engl. J. Med.** 305:1431-1438.

The word "homosexuals" was dropped from the title of the first MMWR article on the new disease (see Shilts 1987:68-69), but it remained its distinctive feature. The patients of the mysterious cases of lymphadenopathy, immune collapse and strangely lethal common infections, patterned in a way that might be characterized as a specific syndrome, were not transplant or leukemia patients, nor did they have genetic disorders, nutritional deprivations, or old age; they were young, male and homosexual. This "presentation of actors" remained forever associated with the new disease/syndrome and influenced almost all its aspects, in both negative and positive ways (see Oppenheimer 1988).

The AIDS-homosexuality link generated a synergistic interaction between homophobia and prejudices about disease and death. Deeply embedded fears of contamination and contagion added to the generic prejudice surrounding lethal diseases (see Sontag 1979, 1989) and were magnified in turn by the fears and prejudice about difference related to sexual life-styles. As a consequence, patients were often rejected and neglected in health providing services, work places, residences, and families (see Gorman 1986, Mondragón et al. 1991). People were secretive about their health and serological status, and individual and collective denial retarded prevention. In Brazil, the very term **de risco** (of risk, at risk) became overloaded with

stigma and meanings of guilt, turning into a derogatory expression.¹¹

Even though epidemiology established other categories of risk for AIDS (the "high risk groups"), homosexuality was the most associated with the disease. Somehow, the stigma that was already attached to AIDS was inherited by the newly defined categories. **Injecting drug users** were equated with inner-city pariahs, as deserving of their illness as the "sexual perverts" were. The poorest among the already deprived Caribbean peoples, **Haitians** fitted in a symbolic lower level of the social hierarchy. And **hemophiliacs** were already sick by definition. As the dynamics of the epidemic and its conceptualization added and dropped some categories (Haitians ceased to be treated as a risk-group, women and infants were added, and more blood-recipients became visible), public opinion and the media indulged in the distinction between the "innocent" victims and the "guilty" ones,¹² differentiated by moral

¹¹This observation, made by Brazilian analysts in the beginning of my fieldwork, was actually quite ingrained in the population, as I could confirm a few years later in a talk on AIDS prevention in **Casa do Brasil**, a community association for Brazilian migrants in Lisbon, Portugal. The fact that speakers had stressed the increased risk of migrant populations (as more vulnerable from a social and economic perspective) for health hazards, including AIDS, offended one (migrant) member of the audience who felt stigmatized with the statement, as if it implied he was also promiscuous and gay.

¹²For an accurate reporting of the history of media's approach to AIDS, see Kinsella (1989).

judgments that remind the theme of the "deserving" and "undeserving" poor.

Leaving to a later moment a more comprehensive discussion of risk groups and the social construction of epidemiology, I will focus now on the central association between AIDS and homosexuality. The very link that enhanced stigmatization and dismissal, and delayed research funding, also helped to channel into the fight against AIDS a very special type of energy and mobilization: the activism which had in the previous decades built the gay movement. It brought organizing know-how and community support to a collective movement that changed the face of the epidemic and expanded the possibilities for those directly affected by it (see Horton 1993). Also, the association of AIDS with sexual transmission and a specific sexual category motivated ample research on sexuality throughout the world, and brought to mainstream medical thought and public policies what had once been esoteric language and gay-ghetto culture. Furthermore, this link, which is at once a social construction and an objective reality, has an impact on the fight for civil rights based on sexual orientation in settings where these were hardly conceivable. In many countries throughout the world, the international fight against AIDS helped strengthening little local gay groups as a tool for implementing prevention and community support for the sick.

The literature has shown that the cross cultural use of the category "gay" may be inadequate and ethnocentric (e.g. Davis and Whitten 1987, Caplan 1987, Fry 1995, Greenberg 1988, Guimarães 1977, Lancaster 1994, MacRae 1990, Mass 1990a, 1990b, Murray 1995, Parker 1987, 1989b, Parker and Carballo 1991, Plummer 1981, Whiten 1979). In spite of the fact that homoeroticism and same-sex spontaneous or ritual practices have been documented for virtually every society and historical period, a distinct identity for homosexuals is available in only a restricted number of them, and mostly for discriminatory purposes. The use of the category gay/homosexual for purely descriptive terms in a medical context, as in the initial reports on a new mortality form published in the MMWR, could hardly be found outside the United States after the seventies, that is, after the gay rights movement. It is therefore possible to argue that the social category "gay" as we know it resulted from the history of struggles for civil rights and became a component of North American culture from the seventies on.¹³ This was not the case in other countries,

¹³Spontaneous comments from Latin Americans and Mediterraneans on the characteristics of the gay movement and gay culture link it to the Protestant ethic and the puritan tradition of domesticating the impulses and having a full transparency between the social and the intimate persona. Some (though not all, for some others raved about U.S. gay culture) of my Brazilian informants despised the ghettoization of homosexuality and what they saw as regulatory and labeling manias of North Americans; instead, they praised a full liberationism where impulses could be enacted independently of identities, and were not supposed to be regulated or even disclosed. For a culturalist

where "gay" is not spontaneously used as a descriptive category in medical literature. Randy Shilts commented on the fact that French researchers dealing with the first cases of AIDS, which they saw as mostly African, considered the label "homosexual" for the epidemic as a very North American thing (Shilts 1987:117,511).

More than a decade of fighting for civil rights for gays and lesbians, modeled on the fight for civil rights by African-Americans and also inspired by the Women's movement, had made the category "gay" visible and turned it into a symbolic site for individual and collective pride. If the process had not erased homophobia, as the Black movement had not erased racism or the Women's movement had not erased sexism, the gay movement had at least created the possibility of emptying the term of its prejudicial content and investing it with positive feelings in specific contexts. In cities like San Francisco and New York, an industry of gay-identified services flourished. They included gay-owned businesses with gay employees catering to gay clients on either gay or general issues, which included bookstores, travel agencies, moving, real estate,

analysis of these discourse, see Parker (1991). I should add that the comment about the Protestant ethic should be contrasted with the Roman Catholic (Iberic version) background of Brazilian culture, its intangible ethical requirements, and its assumed margin for deviance and forgivable sin.

restaurants, bars, bath houses, and other industries of entertainment and commerce, as well as support services such as psychotherapy, medical referrals, dentistry, legal services, housing, twelve-step groups, religious services, and the like. Also, medical text-books carried entries on diseases affecting homosexual men, such as intestinal parasites, dermatological ailments and sexually transmitted diseases.¹⁴ This was a change from the older psychiatric manuals which listed the category "homosexual" as a mental illness.

The independence of gay identity and communities in early 1980s urban North America could be found hardly anywhere else except in a few Western European urban environments. This state of things would change with the development of responses to the epidemic and efforts to implement worldwide prevention (see Altman 1987, 1988, 1995). But, at that time, the layout of sexual categories and the spectrum of sexual behaviors, choices, practices and ideologies was for most of the world arranged in a different manner than the bipolarization between

¹⁴The most quoted "new diseases" that followed the sexual revolution and the multiple partner sexual pattern included Hepatitis B, syphilis, venereal warts, and, by the mid 1970s, also amebiasis, giardiasis and shigellosis (Gorman 1986:162). As far back as 1978, an article on the "gay bowel syndrome" was published in **Emergency Medicine** (Mass 1990a:133). Prepared before HIV was even known, a single topic medical book with the title **AIDS and Infectious Diseases of Homosexual Men** was published by two New York doctors in 1984 (Ma and Armstrong 1984).

heterosexuality and homosexuality that prevailed in the U.S.

Realizing both the lack of knowledge and systematic data on human sexuality (see Davis and Whitten 1987) and the need to understand it better in order to promote AIDS prevention (e.g. Cagnon 1988, Carballo 1988, Carballo et al. 1989, Gorman 1986:170), academics pleaded for funding and engaged in a number of studies on sexuality. These studies illustrated the diversity of sexual categories, behaviors, ideologies and practices across the different cultures, internationally, and within the U.S. (e.g. Cagnon 1988, Carrier 1989, Davies 1989, Davies and Coxon 1990, Herdt et al. 1991, Parker 1987, 1988, Parker, Herdt and Carballo 1991), as well as their implications for AIDS prevention programs. Initially reifying the pre-defined groups as if they were independent cultural systems, these studies showed variation across and within established categories of analysis, whether they referred to ethnic minorities or to transmission groups, like Latinos, African-Americans, women, drug-users, gay men, or blood-recipients.

One of the concerns of this line of research was to account for bisexuals and other men involved in high risk behaviors for HIV infection who, however, did not identify themselves with any of the traditional risk groups or

target groups¹⁵. Research findings showed that the categorization of a distinct gay identity does not account for all same-sex behaviors, and that targeting gay men in prevention programs would not reach many of those who are in fact at risk. Among others, anthropologist Richard Parker argued that in Brazil a rhetoric addressed to gay men, which lacked of cultural-specific adaptations, would exclude from the audience a large number of those at risk, including the men who structure their (homo)sexuality under other lines of identity, such as activity/passivity or transgression (see Parker 1987, 1988, 1991a, 1992). Some Brazilian activist organizations, like ABIA (see chapter 4), asked for more radical reframing of sexual groups and prevention targets; a number of Brazilian social scientists developed AIDS-related sexual research (Loyola 1994, Paiva 1992, Parker 1992, 1994b, Parker, Mota et al. 1994).

The acknowledgement of such variation helped replacing, both in academic questions and in outreach and prevention programs, the static term **identity** with the more dynamic one of **behavior**. An evidence of that shift is given in the chronology of WHO documents on AIDS. In 1988, the agency had entries on "homosexuals." One year later it had

¹⁵The first time I read about this topic in print was in a report in the AAA newsletter, in the years 1987-88, expressing Richard Parker views on the Brazilian. Parker published later a number of articles addressing the issue both from a theoretical and from an applied perspective (e.g. Parker 1987, 1988, 1992).

acknowledged the limitations of that category and replaced it with the more descriptive concept of "men who have sex with men."¹⁶ A similar shift was made from "drug abusers" (WHO 1988b) to "injecting drug users" (WHO 1989a).

The AIDS-related studies on sexuality, though numerous and extensive, did not constitute a unified corpus with methodological consistency. In their first stage, which roughly coincided with the second half of the 1980s, they failed to account for the role of AIDS intervention programs in the legitimation of gay identities in settings where they did not fully exist. A second wave of studies included as an important variable the element of AIDS-induced gay activism, and tried to understand its role in the full picture of sexual landscapes and possibilities for AIDS prevention programs (e.g. Larvie 1995, Mota 1994, Valle 1994).

The communities where the epidemic became most visible, in New York City and California, were also the sites where gay activists had been vocal for more than a

¹⁶The popularization of the term "men who have sex with men", sometimes MSM, did not necessarily meet general success. A young informant of Michael Pollak (1988) considered it a useless euphemism, which sounded like "going back to the closet" after having gone through the hardships of acknowledging his sexual identity.

decade, creating social visibility, and claiming individual rights as well as dignity for a life style defined by same sex orientation, fighting discrimination, prejudice and homophobia, and therefore attracting gays from all over America. In some sense, also, the efforts to make this social identity visible and viable went hand-in-hand with a naturalization of the sexual/social categories, frequently slipping into an essentialization of sexual preferences. Whether explicitly or not, and mostly to oppose the blame theories condemning homosexuals for their acts, many within the gay movement assumed that sexual orientation is an innate characteristic rather than a choice that can be manipulated by will (see Mass 1990a, 1990b).

The taste for naturalization within the gay movement was expressed in the celebration of the "gay gene" research (e.g. Burr 1995), supposed to provide hard empirical evidence of a biological basis for homosexuality. It may seem a paradox that biological determinism is welcomed by the same community that worships Foucault (Halperin 1995) and whose aim seemed once to be the full emancipation from the chains of determinism.¹⁷ These contradictions only

¹⁷In the Brazilian gay settings I observed, the "gay gene" theory, rather than applauded, was mocked as homophobic. Even when comfortable with their sexuality, my gay informants did not like to attribute their sexual orientation (which they would rather call their "sexual option") to biological determinism. "If they tell me it's in the genes, I'll be heterosexual just to show that they are wrong", I heard once as a comment on the theory.

reveal the internal diversity of the gay movement, within which libertarian anarchists co-exist with conservative Republicans and all sorts of ideologies and theories are available.

That such political diversity is held together by claims to a common identity defined by individual characteristics seems to be coherent with North American social and political history. The women's movement and the Black movement were also structured around a collective identity within which there were class stratification and different ideologies, political orientations and lifestyles. Internal diversity did not annihilate the strength of those social movements, which were externally defined as of "lacking" something, and which adopted the strategy of identity reinforcement with the either/or oppositions (Black/White, women/men) that had been at the root of prejudice and discrimination. A similar opposition, homosexual/heterosexual, or gay/straight, was central to the identity politics of the gay movement in the U.S. Seen from the outside, for instance from Brazil, where a number of nuances between heterosexuality and homosexuality exist (as well as they are conceived to intermediate between "Black" and "White"), an absolute dualist system seems strange and alien.

It is also odd that this dualism prevailed in spite of the decades-long availability of the Kinsey reports (e.g.

Kinsey et al. 1948, 1953), which portrayed human sexuality and sexual orientations as a fluid variation along a nuanced continuum where exclusive homosexuality and exclusive heterosexuality were just the extremes. As politics structured ideology and identity, independent gay communities became a social reality as much as a historical product, absolute and contingent at the same time. Both facts must be considered as we examine the explosion of AIDS and its social, political, and epidemiological consequences; the early identification of AIDS and gay men can be seen, at once, as an epidemiological fact **and** as a social construction. This double characteristic became imprinted in the way AIDS was addressed throughout the world, whether it was locally related to male homosexuality or not (see chapters 3-4).

The social response to AIDS capitalized on gay activism -- even though the early responses of gay communities to the association of a new disease with their life-style had mostly consisted of denial (see Shilts 1987). Also, the "gay community" represents a diverse universe, and the sector most early affected did not coincide with those who were more political, but rather with the disco-party, bath-house and beauty crowd (see Shilts 1987).

A gap between the actual epidemic and its awareness characterized the initial years of AIDS. Different theories and explanations co-existed and confused people. Self-blame perceptions introjected the blaming-the-victim ideas of the so-called Christian Right. Views of conspiracy and genocide co-existed with them. Biological warfare, swine flu, chemically induced illness, and other explanations fed and still feed the popular fantasies to this day. Some authors become the voices of dissent in a field where not even the scientists arrived to full consensus (see Fujimura and Chou 1995). Within the popular press, **New York Native's** editor Charles Ortleb became notorious for consistently dismissing not only the HIV-AIDS link but the entire concept of AIDS as a separate disease or syndrome, leading the paper into a systematic opposition to the AIDS mainstream. Years later Native writer John Lauritsen dedicated his book demolishing AZT as a "prescription poison" (Lauritsen 1990) to a page-length list of "AIDS dissidents," those who challenged the HIV-AIDS link and the mainstream AIDS establishment. Also a few years later, the **Spheric** (1994), a student newspaper of the CUNY-SUNY system, addressed the AIDS issue with a special cover article entitled "Is AIDS a Hoax?", questioning the HIV hypothesis and quoting anti-HIV theories from retrovirologist Peter Duesberg (1987, 1989, 1992, 1994), known for his public dissent to the currently accepted theories. The group HEAL, working out of the Gay

Community Center, also adopted anti-HIV theories throughout the time and supported Duesberg's views. Almost fifteen years into the epidemic, they welcome the fervorous anti-HIV crusader Robert Willner, M.D., who targets the "AIDS establishment" and Robert Gallo in particular (see Prescott 1994). Claiming that AIDS is just the lumping under a new name of many different immune-related diseases, a point that is shared by other dissent yet more scholarly authors (e.g. Root-Bernstein 1993), Willner adopts the flashy title **Deadly Deceptions: The Proof That Sex and HIV Absolutely Do Not Cause AIDS** for his book, discourages people diagnosed with AIDS from taking AZT, and accuses the perpetrator of the AIDS hypotheses as "guilty of criminal fraud and murder" (Prescott 1994).¹⁸

If radical dissent and the diversity of background hypothesis evolved to the fringes of the AIDS world throughout the time, as consensus on the role of HIV crystallized and consolidated both for scientists and for

¹⁸To make his dismissal of the HIV hypothesis more convincing, Willner punctures his fingers with blood of ELISA positive people in public shows. In his view, ELISA tests do not mean much, for they react positively to most infectious diseases. An odd spectacle of diversity in perspectives on AIDS could be seen at the Gay Community Center in New York on the evening of November 16 1994. Upstairs, the group HEAL had invited Willner for a talk, while in the main room the most important gathering of AIDS activists evaluated the situation of the HIV epidemic in New York, the Town Meeting on the topic **Are We Surviving? The State of HIV prevention in the Gay and Lesbian community.**

activists, in the early days of the epidemic confusion ruled. In a context of homophobia which most gays had to personally endure to achieve self- and social respect, many of the basic public health prevention measures, such as the attempt to close gay bath-houses in order to stop chains of transmission, were not taken lightly by the community. They seemed an attempt to destroy what little had been achieved. The preventive screening out of gay blood-donors, at the time when the cause for the disease was still unclear, was not taken lightly either; within a homophobic background, such screening seemed to discriminate against gays (see Shilts 1987). Peer exhortations to reduce the number of sexual encounters, limit the exchange of bloody fluids or stop having sex altogether until there was more knowledge about the epidemic, as some physicians had suggested, were rejected as internalized homophobia and erotophobia.

Those who spoke out against promiscuity, like Michael Callen and Larry Kramer, were equated with moral majority preachers blaming gays for their own life-styles.¹⁹ The crowd rejected the messengers of bad news and the

¹⁹Kramer was charged with homophobia and anti-eroticism in a letter signed by Robert Chesley in the **New York Native**, December 21 1981 (see Kramer 1989:10, Nussbaum 1991:94), and Callen, who co-signed with Richard Dworkin and Richard Berkowitz the famous/infamous "We Know Who We Are: Two Men Declare War on Promiscuity" (**New York Native**, November 8-12 1982) was attacked as a "sexual Carry Nation" and rebutted in the same newspaper by infuriated letters (Nussbaum 1990:98-99, Shilts 1987:209-210).

portrayers of less glamorous pictures of the gay life-style. This rejection was extended to the book **And the Band Played On** (Shilts 1987),²⁰ published a few years into the epidemic, which depicted the early years of AIDS denial within the gay community.

As the epidemic continued to ravage American gays and medical evidence about its virological etiology and modes of transmission mounted, denial was replaced by acknowledgement that action should be taken. Drawing on published accounts (Arno and Feiden 1992, Burkett 1995, Callen 1990, Kramer 1989, Mass 1990a, Nussbaum 1990, Shilts 1987, Van Vugt 1994) and on personal witness, I will concentrate the analysis of the social responses to AIDS on the East Coast, and particularly New York City.

AIDS activism in New York City will be analyzed in detail later on this chapter as divided into three main periods: (1) the early responses and the creation of **Gay Men's Health Crisis** (GMHC) and the **People With AIDS**

²⁰The book was severely criticized not just for giving an image of irresponsibility in the gay community; this criticism would later be retracted by its own authors, who admitted that if the community had listened to the warning signs more responsibly, many lives might have been spared (e.g. Feinberg 1994). **And the Band** was also heavily condemned for wrongfully portraying real people, alive and dead, as having thoughts, words and intentions the author could not possibly have known. Making a culprit of Gaetan Douglas, the Canadian air steward portrayed as "patient zero", and demonizing the promiscuous anti-hero, Shilts misrepresented a multicentered epidemic process and fed popular myths and stereotypes.

Coalition (PWAC), related to the emergence of the PWA (person with AIDS) identity; (2) the peak of activism with the beginning of the **AIDS Coalition to Unleash Power** (ACT UP) and the implementation of **Community Research Initiatives** (CRIs); (3) the decline of street activism and the growth of inside-the-establishment intervention and negotiation with the governmental agencies, scientists and pharmaceutical companies; this contemporary period coincides with the end of C.R.I., which was replaced by C.R.I.A. (Community Research Initiatives on AIDS, attached to GMHC), the formation of **TAG** (Treatment and Action Group), and the shrinking of ACT UP, with the loss of many of its members to AIDS, collective burn-out, and various political disagreements.

Another epicenter of the epidemic in the U.S., the West Coast, had a different yet parallel history of fighting AIDS. San Francisco and Los Angeles created their own institutions, some of which are counterparts to those in New York, like **Project Inform**, which started activities as early as 1985 as an alternative to the slow and inefficient pace of medical research and its minimal response to the AIDS crisis, as well as what seemed then the overzealous slowness of the FDA process for drug

approval,²¹ the **AIDS Foundation**, the **Healing Alternatives Foundation**, the **County Community Consortium of Bay Area HIV Health Care Providers** (CCC), the **Shanti Project**, previously created for people dying with cancer and for that depicted as the agency that was "in the right place at the right time)" (Perrow and Guillén 1990:114), and the wide circulation newsletter **AIDS Treatment News**, which started in 1986. Other urban centers were partly tributaries of the bi-coastal development of activism; Boston, Washington, Philadelphia, Chicago, Toronto and other cities founded their own ACT UP chapters, PWA associations, and AIDS service organizations. The remaining states experienced a kind of "second wave" of activism a few years later, as the epidemic expressed itself with a time gap from the major urban centers.

²¹Lead by Martin Delaney, **Project Inform** wanted to shorten the long wait to achieve life-saving information, and systematize the knowledge on what was already used in the community on empirical grounds. Commentators attribute Delaney's commitment to make drugs available, even if they are toxic, to his previous experience with trials for hepatitis, which he survived with an experimental medication that produced neuropathy as a side-effect; others, who did not have access to the medicine due to its toxicity, lost their lives. **Project Inform** aimed "to conduct community research and monitor progress of patients using unapproved medications. But this mission proved to be ahead of time" (Arno and Feiden 1992:32). By then, it was not possible to fund such a venture. The activities then shifted to making available knowledge on experimental and over-the-border drugs, when Mexican pharmacies sold *rivabirin* and *isoprinosin* without prescription, to the excitement of California's gay community.

European countries and Australia had their own versions of AIDS activism, and their formulas for community-based service organizations (see Altman 1995, Carter and Watney 1989, Feldman 1994, Watney 1994). Among the most visible were the **Terrence Higgins Trust** and the **Body Positive** in London, **AIDES** in Paris, and the **Deutsche AIDS Hilfe** in Berlin, with its counterparts **Swiss AIDS Hilfe** and **Osterrreich AIDS Hilfe**. These were large scale organizations that not only provided a number of local services but eventually gave expert assistance to smaller organizations abroad. It is no coincidence that these services and movements appeared where there had been some experience with democracy, civil rights, economic prosperity, and some expression of gay rights.

The developing world, as will be seen in chapters 3 and 4, had a completely different experience. The accumulated absence of democracy, and the often decades-long persistence of military or civilian dictatorships prevented the possibility of any kind of activism defined around individual and non-mainstream rights; if there was any, local activism was directed at more basic and general social goals. In most of the developing world, AIDS activism flourished in strict cooperation with development agencies, as they injected money, models, infrastructure and technical know-how to help local efforts against the epidemic. In most African and Asian countries it is almost

impossible to trace any connections between AIDS action and local gay activism, because the latter was virtually non-existent. However, local AIDS action was influenced by international gay activism not only through its impact on central agencies but also by the presence of overseas gay activists engaged in the development of global action. This is also true for Latin America, which combined the several components of AIDS action with pre-existing currents of political activism in a way that deserves further analysis.

The Brazilian situation will be analyzed in more detail based on fieldwork in Rio de Janeiro between 1989 and 1992, with three follow-up visits. Even though there had been some gay activism in urban Brazil in the late 1970s,²² expressed in the newsletter **Lampião**²³ and the

²²The equivalent to gay life in the seventies is depicted by Frederick Whiten (1995 [1979]) as the culture of **entendidos** (literally, "those who understand it," meaning "insiders"). The topic was also developed by Carmen Guimarães in an academic thesis (1977). According to a local myth (MacRae 1990), it was the visit of the **Gay Sunshine** editor, the one which produced the 1979 piece, that had motivated the Paulistans to organize some sort of gay group, from which **SomoS** would develop.

²³For a short but highly visible period of time, between 1978 and 1981, and gathering credited journalists, intellectuals, activists with political ambitions, writers, and social scientists from Rio de Janeiro and São Paulo, **O Lampião da Esquina** served as a forum for discussing the contradictory ideas and choices on homosexuality and the politics of sexuality.

group **SomoS**²⁴ (see McRae 1990, Mott 1995), the bulk of responses to AIDS did not directly relate to that movement.²⁵ It adopted the language of international development agencies combined with local expression of general social activism and the quest for human rights. It was not in the early moments, but rather at the later stages, that AIDS activism connected to the gay movement, and in a very peculiar way: sponsored by the government and the World Bank aid programs (see Larvie 1995).

In New York City, the earliest responses to the new epidemic preceded the coining of the term AIDS. Fund-raising for research on Kaposi sarcoma, meetings to discuss

²⁴SomoS was a São Paulo-based organization with a symbiotic relationship with the newsletter **Lampião**. Those two social forces represent the peak in gay visibility and organizing; yet, they succumbed before turning into something wider. By the time AIDS became an issue in Brazil they no longer existed as organizations. However, they had left personal and political marks in those who later went through the epidemic one way or another.

²⁵An exception is the GGB, **Grupo Gay da Bahia**, in the capital of the Northeastern state of Bahia, which early alerted its clientele to the "gay cancer" reported in the U.S. and whose leader, Mott, also preached for monogamy. In Rio, the gay group **Atobá**, working out of a poor suburb with a majoritary working class and low rent clientele, also included AIDS awareness in its activities. When internationally sponsored AIDS-NGOs like ABIA (see chapter 4) took the leadership of AIDS action, the small and poorly-funded gay groups could hardly compete in the scene.

"AID" (Mass 1990a:143), as well as a number of articles in the **New York Native**, then the most popular and almost only gay publication,²⁶ may be reported as the first expression of a public reaction to the epidemic. These early gatherings led to the creation, in 1982, of the first and what was to become the major AIDS service organization in the world: the **Gay Men's Health Crisis**.²⁷ The organization benefited from pre-existing networks within the settled down, middle-class gay communities of Manhattan and Fire Island, rather than the more politicized veins of the gay movement. According to chronicler Randy Shilts, there was resistance to adopting politicized leaders in the action against the disease, for they were seen as "downers" by the crowd who was most at risk. Instead, guidance was given to the more glamorous and attractive club types. The first directorship of GMHC, for instance, was given to handsome yet semi-closeted corporate executive Paul Popham and not to the out-of-the-closet writer and recently-made activist Larry Kramer, who had created the agency almost single-

²⁶The **Native** was one of the first publications to give regular support to the topic of AIDS, including in its medical issues section, signed by out gay physician Lawrence Mass. However, its editorial policy evolved into a permanent challenge to medical consensual knowledge, and editor Charles Ortleb became known by his vehement attacks on current beliefs on HIV and AIDS, always writing "AIDS" within quotation marks.

²⁷The original founders were: Larry Kramer, Paul Popham, Nathan Fai, Paul Rapoport, Lawrence Mass and Edmund White (Mass 1990a:122).

handedly and organized the first fund-raising out of his own living room.

GMHC started on a volunteer basis, seeking its own fund-raising and recruiting volunteers from the personal networks of the initial core-group. Motivated people were those who saw their friends and lovers die, or felt themselves sick or at risk. Little was known about the new disease and what could prevent it. The government and the city were not doing anything about it either. The authorities did not seem to be interested in getting involved with a problem of gays, and the community had to take the initiative to do something. GMHC's initial team did their best to create awareness among the gay population and encourage the community to reduce what might be the life-style associated causes for the new disease.²⁸ There was not a consensus around such issues. Opinions varied from stopping sex altogether, to completely denying the

²⁸In their second newsletter, in January 1982, GMHC warned the community that "Physicians are currently advising their gay patients, especially those who live in urban centers with large gay communities, to limit their sexual activity by having fewer partners and by selecting partners who are known to be in good health and who are themselves limiting the number of different partners with whom they have sex ... apart from abstinence, monogamy represents the lowest risk potential" (Mass 1990a:116). Knowledge moved rapidly and this type of phrasing was soon replaced by more efficient, community-based suggestions, like the practice of safer sex. Years later, if epidemiologists and public health officers used a similar line (like "reduce the number of sexual partners", used once by the Brazilian government), they would enrage community advocates.

link between sex and AIDS. With more evidence about HIV and its transmission, lines of consensus about safe-sex guidelines were established.

There was also discussion and disagreement about how to manage the care for the ill and dying. GMHC developed programs to assist people experiencing the ills of the new epidemic, including going through terminal disease. The quite successful "buddy" system assigned a volunteer to a sick person for personal, psychological, and practical support; many people in the city did not have any relatives or healthy friends to rely upon for the most basic help. Yet, dying people often needed more than a volunteer buddy could provide. Whether the agency should offer a more complete type of home care or instead lobby and demand it from the city and state became an issue of disagreement within GMHC. This structural tension did not destroy the agency, but it created a division between the option of providing assistance directly and of fighting on political grounds for the government's obligation to provide the necessary services.

In spite of its "less political" vocation, the agency had strong community support and reached out for more and better links with it. GMHC created a popular information hotline and developed extensive outreach programs, which were initially designed to target gay men, and later adapted to other populations. Research among the community,

and conducted within the terms of the subject, "reaching out for subjugated knowledge" (Reinfeld 1994), was the basis for the development of prevention programs. These assumed a variety of forms, including safe-sex workshops, erotizing safer-sex, clean needles, relapse prevention, and communicating with partners. According to the agency's former director of education,

GMHC's success developing efficient, effective prevention programs lies in the fact that our educational efforts are rooted in the values, experience and language of the people we serve. (Reinfeld 1994:180)

The fact that the community was central to the design and language of the programs brought in a type of knowledge, data and techniques that would hardly have been produced by "experts" in medical science or public health, no matter what their good intentions might have been (see Reinfeld 1994). By focusing on the insiders' knowledge and attempting to incorporate it into every action, this agency was at the forefront of a new form of producing knowledge.

Another sector where GMHC developed know-how from scratch was HIV-test counseling -- pre-test counseling, test decision making, and post-test counseling. Knowledge was produced in the making, for the novelties of AIDS and the set of interacting variables hardly had a match in the history of medicine.

GMHC later became a major institution with permanent staff, large federal funding, sophisticated headquarters in

Manhattan's West 20s, and a relatively heavy structure. Under its prominent institutional persona, it was criticized right and left. Conservative forces were shocked by the explicit sexual references and imagery in the preventive educational materials. Senator Jesse Helms diatribe against funding AIDS prevention, for instance, was originated in his distaste for a GMHC leaflet targeting gay men; his opposition to federal funding for AIDS precipitated a long history of antagonism between the gay community and the supporters of the North Carolina senator.²⁹ Radical activists, including founder Larry Kramer who left the group after one year, were disdainful of the agency's vocation to serve within the establishment, like "a bunch of Florence Nightingales" (Shilts 1987:557), instead of questioning its policies.

While GMHC became a landmark institution visited by representatives of many states and countries, creating models for providing services to people sick with AIDS and developing strategies for education in prevention and support, a different AIDS-related social movement developed through an East-West coast joint effort. The **People With AIDS Coalition** emerged at a meeting in Denver between several people living with AIDS who were tired of being

²⁹The boycott of Helms' funders included the most popular cigarette Marlboro, whose ads had targeted and attracted modern gay men.

"patients," or "clients" of agencies (read GMHC), and having people decide for them (see Harrington 1994:160). Most vocal among them, Michael Callen³⁰ from New York and Bobbi Campbell³¹ from San Francisco, were central in the creation of the Denver Principles and the new resistance identity of **People With AIDS** (PWAs). The concept was a refusal "of the label victims, which implies a defeat," and a departure from the concept of permanent patient, "which implies passivity, helplessness, and dependence upon the care of others" (PWA coalition 1985).

PWAs were the best experts on their own disease; they instilled a new and unique type of contribution to medical

³⁰Michael Callen was widely known for several reasons. A quite vocal PWA, he had a strong connection with his physician Dr. Sonnabend and supported the latter's multifactorial hypothesis for AIDS. They believed AIDS was caused by a number of interacting variables, including Cytomegalovirus, the Epstein-Barr virus, repeated exposure to drugs and sperm, and the use of drugs like poppers. Evidence came from the fact that people who got sick with AIDS were also the ones with a higher number of sexual partners, and the correlate variables of more sexually transmitted diseases, more antibiotic treatments, more exposure to drugs, and more contamination by other viruses and microbes. Speaking out against the promiscuity that he had once epitomized, Callen was bashed by the community and several replies flowed over the next few years in letters to the New York Native and articles. He outlived his diagnosis for many years, and his faith in the multifactorial hypothesis made him distrust antivirals like AZT. For that, he continued to be a polemic figure.

³¹Rather than a politico, Campbell was a festive member of the "sisters of perpetual indulgence". His was one of the earliest public disclosures as a person with AIDS, and become referred as the was "Kaposi sarcoma poster boy".

practice and science. Also, the response to AIDS became at least nominally detached from gay identity, allowing different people affected by the disease to join in the movement. In years to come, GMHC also expanded its clientele and, in spite of keeping the original name, started serving women, minorities and other clients whose identification was not primarily gay.³²

Several analysts of the PWA movement (Harrington 1994, Nussbaum 1990, Wolfe 1994) define it as a tributary of the feminist health movement. The women's lib motto "the personal is political" and the collective **Our Bodies, Ourselves** (Boston Women 1973) provided inspiration for self-empowerment and liberation from the predicaments of patriarchal medicine. While medical knowledge defined AIDS as a lethal disease with no hope after diagnosis, the "patients" reacted and claimed their condition of People With Aids (PWA) as **living** with AIDS, rather than passively waiting to **die** of it in the next few months. The impact of this movement included achievements in treatments, quality of life, and preventive education developments. It had echoes in many places; in Brazil, for instance, people adopted the description of **pessoa vivendo com AIDS** (person

³²Contradictory narratives depict that transition as either a smooth one or as almost inexistent. Even though the current figures furnished by the agency portray a quite diverse array of clients, a number of people from minorities report feeling excluded by an organization that has a predominantly white gay history and culture.

living with AIDS), rather than the medical term "aidético," which had the connotations of terminal disease and all the stigmas attached to it.

The PWA movement had a kind of love/hate relationship with the medical establishment. They had rejected medicine's pompous prediction of their imminent death and contradicted the prediction by living. Yet they did not reject medicine as a whole, like the **New Age** devotees who traded drugs for herbs and meditation.³³ Californian PWAs crossed the border to Mexico for pharmacy drugs that were not permitted in the United States. New York PWAs fought for official trials of the Israeli drug AL 721.³⁴ Coast-to-coast, people took drugs with high toxicity risks and with no proven efficiency. In New York, the People With AIDS Health Group (PWAHG) was a pioneer association for sharing information and drugs that were hard to acquire (see Nussbaum 1990:251). They were not anti-medicine: they

³³The most known of the new gurus was Louise Hayes, whose "Healing Circles" extended from California to the East Coast. For an account of the **New Age** movement, see Ross (1991).

³⁴ AL 721 was basically a lipid concentrate from egg-yolk that worked on the assumption that lipids might prevent the binding of the virus and the cell wall. According to analyst Bruce Nussbaum, who takes a close look at the corporate business behind drug development, AL 721 was not developed because of the rapid development of AZT, which he also attributes to profit and award thinking motivation rather than a scientific and therapeutic breakthrough (Nussbaum 1990).

wanted the doctors to do more, produce more, and know more.³⁵

A second moment of AIDS activism in New York coincides with the development of the **Community Research Initiatives, CRIs**, and, simultaneously but independently, the founding of the **AIDS Coalition to Unleash Power, ACT UP**, in 1987.

Before the official **CRI** was created in 1987, there had already been a series of "guerrilla trials," that is, community based therapeutic research on drugs that might work against AIDS-related diseases. Chronicler Bruce Nussbaum locates the first grass-roots community trial in 1984, coordinated by Dr. Joseph Sonnabend in New York City (Nussbaum 1990:221).

Those trials were the spontaneous answer of community physicians and PWAs fighting for their lives, a group of

³⁵Gay physician Lawrence Mass, involved with the epidemic since its very beginning as a **Native** writer and a founder of GMHC, had a perspective on the relation between the gay community and the medical establishment from both sides. Distancing himself both from patronizing and insensitive medicine and from radical, anti-science activism, he synthesized his "centrist" position as "it's possible to be aware and critical of pseudoscience and homophobia throughout the history of medicine and science, while at the same time respecting that, whatever the political obstacles, our understanding and control of the epidemic must eventually come from our within mainstream medicine and science" (Mass 1990a:123).

people anxious about the slow and inefficient official procedures for approving and releasing AIDS treatments in the United States. Later, they became also a response to the single focus on antivirals by the leading research agencies like NIH and the pharmaceutical corporations. In a way, the movement of people living with AIDS anticipated the possibility of a new paradigm for health and illness, departing from authoritarian models of single agent and single therapy inherited from bacteriology, which have also been referred to as "germ-theory" and "magic-bullet thinking."

But germ-theory was what oriented mainstream research. Like Rifampicin for Tuberculosis, Salvarsan for Syphilis, the polio vaccine, and the antibiotics that defeat most bacterial infections, some HIV-specific "magic bullet" cure for AIDS should be developed. However, the optimism that followed the finding of a viral agent was not accompanied by effective treatments. The ones that were developed, like the anti-retrovirals directed at reverse transcriptase, were neither magic nor precise bullets: their efficacy remains questioned after almost ten years.

The history of AZT development is somehow paradigmatic of the mainstream "magic bullet" approach to HIV and AIDS, even though medical wisdom had traditionally been suspicious about the possibility of treating viruses that way; since viruses "live" as parasites in cells, a "bullet"

would destroy both. However, the recent success story of acyclovir, marketed by Burroughs-Wellcome with the brand-name zovirax, had brought some optimism about viral therapy. Zovirax proved to be an efficient treatment for herpes, a viral infection quite widespread among the adult population in the 1970s. Not surprisingly, Burroughs-Wellcome was the company that helped the National Institutes of Health to develop AZT and later manufactured and marketed it, taking the credit and profit from the entire development of the drug.³⁶

Commercialized as **Retrovir**, AZT was the first drug to target HIV. The affected communities of patients and doctors praised it, and so did the stock market (see Nussbaum 1990). When the drug's efficacy was still barely proven, activists asked for its release. They equated FDA's bureaucracy with murder. People were dying every day; the approval of the only promising drug, even if mediocre, should not be delayed. Volunteers entered the trials so that they had access to what was their only chemical hope

³⁶The development of the potentially anti-HIV new drug started in the NIH laboratories (see Nussbaum 1990). After LAV/HTLV-III/HIV was isolated, NIH researchers screened compounds for anti-retroviral activity. Suramin, the first candidate, was discarded after negative results. **Compound S** existed with no patent and what seemed no use, but showed in vitro anti-retroviral activity. It was zidovudine, or **azidothymidine**, or **AZT**, and it would become the first magic bullet for AIDS. In order to develop the drug, NIH researcher Sam Broder negotiated with the pharmaceutical corporation Burroughs Wellcome for sponsorship and drug supplies for the trials.

for the moment.³⁷ When finally approved, in March 1987,³⁸ AZT was priced at a tremendously high cost, exceeding U.S. \$10,000 a year per person (Arno and Feiden 1992:6,55). Like the FDA and, later, the NIHs and New York City Hall, Burroughs-Wellcome became the target of activists. Anti-greed demonstrations added to the range of political activities in New York and elsewhere.³⁹ After ACT UP's political action, the price of AZT fell but still costed \$8,000 per year. The New York Times described it in August 28, 1989, as the "inhuman" and "extraordinary cost" that made AZT "the most expensive drug in history."

³⁷To avoid taking a placebo instead of the "only hope", some patients enrolled in trials shared their assigned pills with one another in order to increase their chances of having the real product.

³⁸AZT was approved in March 17 1987 and reigned as the sole antiretroviral in the market for five years; ddI, a similar drug (nucleoside analogue) was approved only in October 9 1991 (Arno and Feiden 1992:18).

³⁹AZT was for some time the most expensive medicine ever. This would be beaten by some of the medications developed to treat and prevent AIDS-related infections, which became even more expensive. This was the case with foscarnet, a drug produced by Astra laboratories against CMV-related retinitis and blindness, useful for those who did not respond well to Syntex' ganciclovir. The price of U.S.\$ 25,000 per year for foscarnet turned Astra into a major target for activists (see Harrington 1992:6). In the Eighth and Ninth International Conferences on AIDS, held in Amsterdam and Berlin, activists' anger against the corporation peaked and the entire conference was given leaflets depicting Astra's "Astronomic greed"; the company's exhibit booth was destroyed by a guerrilla attack.

While mainstream research adopted the most sophisticated and high-tech approach to the new medical problem by attempting to develop specific (and expensive) antiretroviral drugs, community research initiatives employed more down-to-earth, life-saving strategies that targeted the multiple infections that actually kill people with AIDS. They also included in their plans for the future the development of immune-boosters. People continued to die with respiratory infections such as **Pneumocystis Carinii** pneumonia (PCP). The New York CRI worked at something apparently simple, yet dramatically efficient from the perspective of those affected: preventing the secondary respiratory infections that kill most people with AIDS. Aerosol pentamidine started being used uptown at Sloan-Kettering and the trials in CRI, as well as in San Francisco CCC (Community Council Consortium of HIV-AIDS Health care Providers), proved to be efficient at preventing pneumonia and saving lives (Arno and Feiden 1992:118). This achievement was so important that it affected the entire therapeutics of AIDS throughout the world. In June 1989 it passed the F.D.A. approval process (Nussbaum 1990:233).

Commentators on this process (Arno and Feiden 1992, Black 1986, Nussbaum 1990, Harrington 1994) emphasize the role of the community-involved physician Joseph Sonnabend, who had already been successfully prescribing Bactrim as a

preventive for PCP to his private patients. He had also done a number of office-run experiments and a community-based epidemiological survey. Turned into a specialist in sexually transmitted diseases by the demand of his Greenwich village clientele (Nussbaum 1990:74-75), Sonnabend had a scientific background which included research on interferon for cancer treatment in Britain. According to Harrington (1994:161-162), Sonnabend's skepticism about a "magic bullet" approach to HIV was related to his previous frustrating experience with interferon in the 1970s.

It should be added that Sonnabend, who had several times expressed his preference for a multifactorial model for AIDS etiology (Black 1986, Moraes and Carrara 1985a, Mass 1990a, Nussbaum 1990, Sonnabend et al. 1984), was consistent in pursuing a clinically comprehensive approach to the organism and preventing secondary infections from being lethal rather than targeting HIV alone. However, HIV was what mobilized most researchers, media, industry, stockholders and people with AIDS, and soon Joseph Sonnabend was marginalized by the mainstream AIDS establishment. In 1985, he was replaced by Dani Bolognesi as editor of the Journal **AIDS Research**, which he had led since 1982. The journal's name was also changed to **AIDS Research and Human Retroviruses**, acknowledging the establishment of the retroviral etiology of AIDS as the

definitive scientific consensus. That same year Sonnabend lost his position in the AIDS Medical Foundation (AMF), an organization he had helped create with Dr. Mathilde Krim for the purpose of funding community research. The original AMF expanded into the cosmopolitan, movie-star led and nation-wide AmFAR, the American Foundation for AIDS Research, integrating similar projects from the West Coast.⁴⁰

Sonnabend's most vocal patient and long-term survivor Michael Callen declared the empowering effect of the multifactorial hypothesis: instead of accepting a prognosis of a six-months of life followed by death from a killer virus, he could take control over his life by achieving some type of balance and preventing secondary infections. Instead of waiting for the NIH and corporations to create antivirals, and the FDA to approve them, he started acting for his health. He shocked many by dismissing AZT, the drug that everybody fought to have.⁴¹ Callen reached out to other HIV

⁴⁰AmFAR grew from the merging of AMF and a project of a parallel organization in California, headed by Dr. Michael Gottlieb and starring Elizabeth Taylor. Gottlieb had been Rock Hudson's doctor, and the later had allocated funds in his will for AIDS research. AmFar later became the major funder of New York's CRI (Arno and Feiden 1992:50, Nussbaum 1990:225).

⁴¹In a polemic cover of the **Village Voice**, Callen was presented as praising love, a good physician and Classic Coke (not dismissing luck), as the keys to his own survival.

infected long-term survivors, aiming to find some common factor that could explain their longevity. Not finding any objective factor for long term surviving, he produced nonetheless a powerful testimonial book (Callen 1990).

The low-profile, sympathetic Sonnabend seems more popular among PWAs, social commentators and journalists (e.g. Black 1986, Burkett 1995, Nussbaum 1990) than among the scientific community. The majority of scientists support a germ-theory approach that singles out HIV necessary and sufficient cause for AIDS, and a "magic-bullet" approach to therapy research and anti-retrovirals development (see Goodman 1995). The few scientists who challenge the mainstream, such as Peter Duesberg or Robert Root-Bernstein, are rejected as mavericks and outcast from the scientific community.⁴² Yet, like most PWAs, Sonnabend

⁴²Duesberg, a virology researcher at the University of California Berkeley, presented a radically different point of view about AIDS and the role of HIV (e.g. Duesberg 1987, 1989, 1992, 1994). In his perspective, HIV is a harmless chain of RNA that has no role in the development of the pathologies related to AIDS; in his model, the occurrence of those illnesses should be attributed to an immune break down caused by the repeated use of drugs, either recreational or therapeutic. Root-Bernstein compiled an amazing quantity of remarks to prove that the established consensus on AIDS and HIV does not fulfill the mandatory requirements for the establishment of definite scientific facts (Root-Bernstein 1993). Both Duesberg and Root-Bernstein had some important scientific credentials on their sides. Instead of working in their favor in the context of possible debates, those credentials were eroded by their public engagement on the HIV-AIDS discussions. Other theorists, as well as real mavericks, have been involved in the discussions; in Europe, a commission for the evaluation of the HIV-AIDS hypothesis met a number of years, deciding every time that evidence favored the HIV hypothesis. Other authors without equivalent scientific

does not oppose the medical establishment nor fully dismiss the role of HIV as Duesberg and others do.⁴³ The contrast between this community physician and the mainstream biomedical wisdom is more a matter of background frame and focus than of incompatible theories such as happens with Duesberg and his followers.

CRI's tested many potential treatments, yet most of the trials led to their being discarded. Many of the wonder drugs that had charmed the AIDS community, from AL-721 (Harrington 1994:174-6) to Compound Q, an extract from the root of the Chinese cucumber that caused discussions and schisms,⁴⁴ showed in the end not to bring remarkable

credentials have also published challenges to the HIV theory (Coulter 1987, Lauritsen 1990), sometimes attracting PWAs and alternative healers. For a thorough discussion of the "Duesberg case" of dissent in science, see Fujimura and Chou (1994).

⁴³I had the chance to contact Dr. Sonnabend briefly in a very interesting moment of the "HIV theory discussions", on the day when the Eighth International Conference on AIDS was disrupted by a **Newsweek** cover-story referring to cases of AIDS without the presence of HIV. The news generated hot debates and press conferences, which I attended as a free-lance journalist covering the event. Unlike others, the physician did not capitalize on the new information to promote personal doctrine.

⁴⁴The New York/San Francisco differences emerged clearly over this topic. Martin Delaney and Project Inform supported the trial, while Callen and, officially, New York's CRI, opposed it for being too toxic. Yet, underground trials were executed, involving even people of the CRI staff. The drug was too toxic and the trials were stopped after some people died.

improvements in the health condition of PWAs. However, a major achievement was made for one of the classical infections of advanced AIDS: **Mycobacterium Avium Intracellular**, also known as MAI. As death rates by PCP diminished, other diseases became more visible and emerged as causes of death, among them MAI. CRIs trials experimented with the drug Rifabutin, which revealed a 50% chance of preventing MAI (see Harrington 1994:171-2).

If nothing else, testing these two therapies, aerosol Pentamidine for PCP and Rifabutin for MAI, saved lives and spared suffering. Having passed through this community-based process of achieving knowledge, those treatments became officially adopted throughout the world. Most of the doctors who prescribe them and the patients who consume them know little or nothing about the community roots of their approval.

The unconventional nature of the CRIs did not spare the project from conventional financial problems. Short of funding and burdened with huge debts, criticized by early supporters for spending much with few results and not publishing in the credible medical journals, it had to close its doors in 1991. To replace it, an institutionally different yet similar project was created as part of GMHC: CRIA, standing for Community Research Initiatives on AIDS.

At that point, and for a number of years, the epicenter of the basic indignation that drives citizens to political activism was located elsewhere: in the unmatched **AIDS Coalition to Unleash Power**, known as **ACT UP**. Nowhere was the fervor of reaction and the drive for action and change as intense as in this group, which generated a new social movement (see Elbaz 1990, 1991, 1992, Gamson 1991, Wolfe 1994).

ACT UP's most reported myth of origin refers to an inflamed speech by the playwright and activist Larry Kramer at the Gay and Lesbian Community Center in New York's Greenwich Village in early 1987. Kramer had been a founder and later a dissident of GMHC. He was also known for preaching to the gay community against the excesses of a sex-centered life-style years before the beginning of the epidemic. His book **Faggots** (Kramer 1978), depicting the excesses of the fast-track urban gay life, had angered many in the community. His message had been despised and neglected: nobody wanted to have the party spoiled (see Shilts 1987), nor see such a caricatured and negative portrait of the community (see Mass 1990a:120-121). After the epidemic started and his own preaching intensified, his message took on a different meaning. His play **Normal Heart** (Kramer 1985) made it to the Public Theater. Loved and hated, depicted as the "Angry Man" (Arno and Feiden

1992:8), or as a "volcano of anger" (Nussbaum 1990:328), he became a central voice in the AIDS movement.

On that evening in 1987, Kramer reminded the audience of his early article "1,112 and counting," originally published in the New York Native in 1983 (see Kramer 1989). Back then, 1,112 had been the number of reported AIDS cases in the U.S. Four years later, there were 32,000 cases nationwide, 10,000 of them in New York city alone. After asking the audience to stand, Kramer used the same phrasing of four years before:

at the rate we are going, you could be dead in less than five years. Two thirds of you will be dead in less than five years ... If my speech tonight doesn't scare the shit out of you, we're in real trouble. If what you're hearing doesn't arouse your anger, fury, rage, and action, gay men will have no future on earth. How long does it take before you get angry and fight back? (Kramer 1989:128)

And he asked for leadership, inciting the masses to organize and do something. He trashed the ways of GMHC, the government, the medical establishment, the slow pace of research, and called for community organizing in order to lobby for the access to drugs; he compared the poor condition of hospitals in New York City to the quality of a center he had just visited in Houston. With a "we desperately need leadership" (Kramer 1989:134), he incited people in the room to get organized and meet again. In fact, two days later about 300 people met in the same room... and ACT UP was born.

However, as activist/commentator Maxine Wolfe (1994) points out, a single speech from a single person does not create a social movement. Kramer had addressed the masses time and again with no major impact. But 1987 was the right moment for him to speak at the right place. Discrimination and homophobia added to a medical and biological fact, and "turned illness into a political crisis" (Wolfe 1994). The seeds for a new social movement had been fermenting for a while; the year before there had been signs of an incipient social upheaval in the gay community, fueled by indignation and anger about the epidemic.

The growth of a new social movement contrasted with a previous period of stagnation. Since the years of GAA (Gay Alliance Activism), inspired by the Stonewall movement, there had not been much street activism. Community action had taken the form of fighting for legal rights and developing community services, the style epitomized by GMHC. GLAAD, the Gay and Lesbian Alliance Anti-Defamation, was founded in 1985 specifically to fight the homophobic, racist and sexist reporting of AIDS, and was depicted as "the first [political] activity in the gay community in 15 years" (Wolfe 1994:218). However, it evolved into a bureaucratized structure in a short time, and the effects of the epidemic in the community demanded more. Anger and despair caused by AIDS brought popular reaction to a boiling point. A street demonstration on Fourth of July,

1986, gathered a protesting crowd of over 5,000 gays, lesbians and friends. While GLAAD tried to keep the crowd under control in a march from Sheridan Square to Federal Plaza, the group spontaneously marched to Battery Park, and showed themselves and their motives to the one million tourists and locals expected for the Bicentennial celebration of the statue of liberty (see Wolfe 1994:219). This type of protest anticipated what would become ACT UP'S style of activities.

The community was anxious and angry: AIDS had killed too many people, there seemed to be no effective cure or treatment, and neither the government nor the scientists seemed to be doing enough to produce them. ACT UP gathered people whose common motivation was "the desire to end the AIDS crisis and the need for direct action" (Wolfe 1994:224).

This was already six years into the Reagan administration, and government inefficiency was so blatant that it was hard not to blame homophobia for the general inaction. Had it been a disease of heterosexuals, activists argued, and all the public means of action would have been mobilized to spare lives and suffering. Some voices depicted the situation as of genocide, mass murder, and crimes against humanity (see Kramer 1989, Wojnarovic 1991). Presidents were called murderers. Reagan, later Bush and even Clinton after the election in which he had promised so

much, were attacked by the activists for not addressing the epidemic. Reagan's silence in the midst of so many deaths was shocking, and his lack of action contrasted with the readiness with which Ford's government had prepared people for a swine flu epidemic that never materialized. The first Reagan-appointed AIDS commission had no AIDS experts, and the popular anger continued. Neither Reagan nor Bush were comfortable with the issue "gay"; they condemned "deviant" life-styles to fit into their constituencies' values. Kramer compared the situation to the holocaust (Kramer 1989), implying that some type of group-specific mass murder took place. The collective endangerment helped raise community consciousness and a very politicized new movement started from there.

The graphic project **Silence=Death** is associated with the beginnings of ACT UP and remained linked with the movements image in the years to come. Conceived in the end of 1986, the project included posters and stickers where a shining pink triangle on a black background evoked both gay pride and past discrimination. Underneath the triangle, the wide, white, sans-serif letters announced loudly that **Silence Equals Death**. Government inaction and silence, community inaction, and negligent laissez-faire all translated into an escalating of deaths. The posters and stickers helped create public awareness and were rapidly adopted by the newly found **AIDS Coalition to Unleash Power**

(see Crimp 1990, Wolfe 1994). The logo was adopted by ACT UP, both in New York and in the many ACT UP chapters that soon started activities around the country and abroad. Later, California created its counterpart **Action=Life** (on a white backdrop), and every major ACT UP action was accompanied by a top quality graphic project: "Seize control of the FDA," "Storm the NIH," "Target City Hall." Keith Harring's artwork was adopted for AIDS awareness posters and T-shirts. Graphics, artwork, sound-bites, and well prepared press releases helped enhance the movement's visibility (for a thorough documentation see Crimp 1990).

ACT UP capitalized on a kind of energy which is hard to replicate and to describe. It brought back the spirit of street intervention. It brought together gays and lesbians who had been separated by different agendas for at least a decade. And it is no coincidence that the new style "Queer Nation" came out of ACT UP actions, bringing a new attitude, ideology and even looks.⁴⁵ A weekly magazine, **Outweek**, was temporarily the twin voice to ACT UP.

⁴⁵Different from the older "gay clone" from Christopher Street, with his trimmed moustache, hair-do, lumberjack flannels and jean jacket, the "new clones" shaved their heads, moved the pocket bandana to their heads, inverted their baseball caps, pierced both ears, kept the same white T-shirt and inhabited the East Village and Chelsea rather than the West Village or the suburbs, as M. Signorile chronicles in **Outweek** snappily depicted. The new fashion statements, themselves inspired and influenced by the hip-hop movement and African-American innovations, were rapidly adopted by other populations.

Those novelties were accompanied by increasing politicization: ACT UP raised awareness about the social problems behind the health crisis that were foreign to many of its members (Elbaz 1992, Signorile 1993). To prevent bureaucracy, ACT UP did not rely on centralization and delegation except for specific and pragmatic purposes. The structures of internal democracy and ordered anarchy meant long and often painful meetings, but they were a guarantee that the bureaucratic centralism which had corrupted previous organizations would not be replicated. ACT UP was able to organize complex street actions, from Wall Street and City Hall in downtown Manhattan to the FDA in Washington D.C. and the NIHs in Bethesda, Maryland. Preparation included teach-ins, training for civil disobedience, and the development of *ad hoc* affinity groups as an original strategy to resist violence. Teach-ins expanded into books and files with information that no one else had compiled, and that were used to lobby and negotiate with the government.⁴⁶ ACT UP's consciousness raising extended from its members to the public. It

⁴⁶For a full account of this process see Elbaz (1992) and Wolfe (1994:225), as well as Feinberg (1995) for an experiential narrative. The data compiled by Act Up special committees contained priceless information. The **Treatment and Research Agenda** and the **Countdown 18 months**, compiled by the Treatment and Data Committee and brought to my fieldwork in Brazil proved to be a priceless tool of knowledge and research, praised by activists and doctors alike.

developed a new style of media-caption with pre-prepared press releases, successful sound-bites and photogenic and telegenic demonstrations. It addressed -- even if it did not solve -- the problems of gender and minority representation within the committees and the constituency in general.⁴⁷ Finally, it created the notion of **AIDS activism** and **AIDS activist** as conceptually different from gay activism. Even though the majority of ACT UP was gay, the group went beyond the ways of gay activism. As commentator Maxine Wolfe notes, ACT UP completed the full circle of politicization the moment the group inspired other social movements, either minority demonstrations, women activism on breast cancer, or other patient-based associations and movements.⁴⁸ Gay and AIDS activists had been inspired by Women and African Americans in the first place. As for its legacy, it was extended to everyone. As commentators note, the slow pace of enrollment in Cancer

⁴⁷Lack of representation of minorities was one of the most cited criticisms to ACT UP. However, it was frequently addressed in general meetings, often split between giving the priority to **AIDS**, regardless of the social implications associated with the struggle, or, on the other hand, bringing in to all the interventions every aspect of the political character of the AIDS crisis.

⁴⁸"Patient empowerment (...) shaped the policy response to AIDS and eventually inspired broader changes as advocates for people with Alzheimer's, breast cancer, schizophrenia and other diseases began to approach their diseases with new militancy" (Arno and Feiden 1992:61). Also, the slow pace of enrollment in Cancer drug trials was highlight by ACT UP and is now an issue at the NIHs (Nussbaum 1990:323).

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For more than five years, ACT UP consistently gathered hundreds of people at its weekly Monday evening meetings. At its high, the crowd did not fit in the main room of the Gay Community Center on West 13th street and meetings were held in the auditorium of the Cooper-Hewitt Building on Cooper Square. Meetings were an exercise in "structured anarchy," where the floor had the ultimate power to vote and decide, no one had more right than others to speak, and interventions were limited to two minutes. The meetings were able to combine the intense sociability of an exuberant and handsome crowd with the ability to get work done. Background preparation from the several committees provided the necessary materials to keep the crowd ultra-informed. A back table held xeroxes of all relevant information for the week, from press clippings to NIH or government information. Empowerment and empowering knowledge distinguished the ACT UP crowd from the rest the interested and uninterested population: everyone there either was or was to become familiar with the complex world of treatments, government politics, zaps, teach-ins,

outreach, prevention, and the like. ACT UP and the "newness" of its strategies have been the subject of several published accounts (e.g. Crimp 1990, Elbaz 1990, 1991, 1992, Feinberg 1994, Gamson 1991, Wolfe 1994).

More than once, tensions arose across the lines of gender and race. The group was often accused of being predominantly gay white boys, who tried to have diversified representation in the different committees but could not always achieve it. African Americans often felt alienated from the group, even though some remained. Latins developed their own caucus, which evolved into the internationally connected **ACT UP Americas**, with links to South and Central American countries. And women had to force their own agenda, which at some point led to the publication of a book on Women and AIDS (ACT UP 1990). The role of women in the group remained a polemic topic (see Wolfe 1994:231-237). Political issues involving gender, race, and class were sometimes seen as distracting by some who wanted to focus only on AIDS; others had become aware that these issues also had to be addressed in order to fully overcome the health crisis.

The decline of ACT UP and the emergence of specialized groups which negotiated within the establishment marks the

third moment of AIDS activism in New York City. Currently, the anti-AIDS movement has split into different directions: first, the agencies that provide services and struggle to keep their funding; second, the remaining grass-roots activists, no longer mobilizing vast crowds, and disdaining both the AIDS industry and those who grew in AIDS activism and that "sold their souls" to be insiders in Washington or sit on the advisory boards of drug companies; and third, those who specialized in drug research and protocol recommendations, like the **Treatment and Action Group** (TAG), and who are more prone to monitoring medical research than to demonstrations or community action.

TAG split from ACT UP in the Fall of 1991 (Harrington 1992:1), gathering a number of activists once prominent in ACT UP and in other community activities, like Peter Staley and Mark Harrington. Its format as a closed and by-invitation-only society was the very opposite of ACT UP's wide open inclusiveness; in ACT UP anyone walking in the door was a part of the "floor" and therefore a **member** with voting capacities. The exclusiveness of the new organization angered some of the old time activists. They spoke out against the careerism of the new "experts," who had traded their ACT UP T-shirts and baseball caps for

corporate-looking suits and ties,⁴⁹ and had accordingly changed their working mind set.

Whether freed from community support or receiving it through other channels, TAG was able to do quite notable work in monitoring research on AIDS at its higher levels. For the first time, the activists' focus on immediately rewarding therapeutic research shifted to include a more comprehensive analysis of the whole picture of on-going research and medical knowledge production, including basic research. Some years after its fast release, AZT was no longer seen as a wonder drug. The results from the Concorde trials,⁵⁰ made public in 1993, helped cast doubts about the efficacy and adequacy of administering the drug to people with an asymptomatic HIV condition, which was then the standard procedure. Pharmaceutical companies and the National Institutes of Health were sponsoring research on other nucleoside analogues like ddI and ddC, which also target reverse transcriptase. Having temporarily excited

⁴⁹This was an observation directed to TAG members by a journalist in a press conference, during the Ninth International Conference on AIDS, in Berlin, 1993.

⁵⁰"Concorde" referred to a French-British multicenter study whose results were released at the Ninth International Conference on AIDS, held in 1993 in Berlin. For many physicians whose "faith" in AZT was doubled by evidence on patients' reduction in symptoms, the data felt like a bomb and caused a temporary epistemological devastation right at the conference. The doctors had been administering AZT to asymptomatic HIV infected people in the full belief that it retarded the onset of symptoms, which was a medical dogma until that moment.

the public and the market, they were not a real breakthrough. Something else was needed, an that included a change in the scope of action and research. TAG worked on helping to define new lines of inquiry that could be adopted by scientists.

At the Eight International Conference on AIDS, held in Amsterdam in 1992, Mark Harrington appeared no longer as ACT UP member but as TAG executive and presented a paper on HIV pathogenesis and activism to a plenary filled with basic-research scientists. He presented concrete ways in which activists may help raising the right questions so that scientists can look in more creative directions for an understanding of AIDS. In that specific paper (Harrington 1992), he reviewed the state of the art and asked central questions on AIDS pathogenesis; arguing that it is worthless to replicate nucleoside analogues like AZT if we still do not know how HIV infects human cells, he called for more cooperation between the community and scientists at the level of basic research. He also asked for more research on one of the more neglected strategies for fighting AIDS, that of immune-boosters. The scientific mainstream had focused on antivirals, and the community research initiatives had produced preventive strategies and treatment for secondary infections, but the understanding of the multiple complexities of the immune system in the context of AIDS, as well as in general, was still far behind.

TAG acted differently from other activist groups by specializing in the language of science, and, to a certain extent, replicating the scientific research mind set. This fact eventually led the group to make choices that were more likely to be expected from scientists than from community advocates. A clear example was the discussion on the release of protease inhibitors. While AIDS activism had always advocated for the fast release of drugs, TAG asked for a longer period so that the mistakes made with AZT should not be repeated. TAG experts had also a unique role in analyzing the entire scope of on-going research on AIDS, spotting duplications and gaps, raising questions to be explored, and giving recommendations both to the NIH and pharmaceutical companies.

ACT UP's special group on Treatment and Data worked parallel to TAG. In 1992 it developed a project named after Barbara McClintock with the purpose of analyzing, supervising and recommending questions and orientations in scientific research. The name of the Nobel awarded corn geneticist (see Keller 1983) was adopted to inspire innovation and creativity in the research on AIDS. On paper, ACT UP's Barbara McClintock project and TAG seemed similar, but the groups evolved differently. Detached from the community, TAG worked as a closed agency of para-specialists; McClintock's project worked in articulation with ACT UP and evolved into the "Cure for AIDS" project.

Cure for AIDS, it should be noted (see Erni 1994), was a inflamed guiding motto and a driving force for a large component of the social movement in the United States.

As I write in 1995, ACT UP still meets on Monday evenings, back at the Gay Community Center, and with fewer people. It holds a number of activities with the media, appears in collective public demonstrations, and does consistent work in the Treatment and Data Committee. However, the organization no longer attracts the large crowds it once did. Its energies are drained, with too many people lost to AIDS or to the consequences of political burn-out. After Clinton's election in 1992, ACT UP put pressure on the White House with a symbolically-loaded and powerful political funeral.⁵¹ As a presidential candidate, Clinton had promised that his office would support AIDS research, programs to assist PWAs, and prevention; however, the new administration failed to keep many of its promises and did not bring any visible resolution to this health crisis.

In 1995, GMHC has its doors open with a staff of 270, mobilizes 6,500 volunteers, and manages a annual budget of U.S. 27.5 million dollars. It directly serves more than

⁵¹Political funerals were very special forms of public intervention, where the body of the person who had just died of AIDS was carried in a combined action of mourning, awareness, and political demonstration. The demonstration in the White House included the carrying of ash-urns and the throwing of ashes.

7,000 people a year and advocates and educates tens of thousands more. In the 1994-95 fiscal year, the agency distributed 750,000 pieces of literature on HIV/AIDS, and its hotline answered 46,000 phone calls. The initially white male profile of its original clientele has changed and is now composed by 41,5% White, 25,1% Black, and 26,8% Latino clients. Heterosexuals now account for 28,4% of clients, and women are 16,4% of those who get services from GMHC (GMHC 1995:1-2).

In a city with an estimated 200,000 people infected with HIV, where the reported cases in mid-1995 exceeded 75,000, and the number of adult deaths had mounted to 48,877, AIDS-service organizations are constantly drained by demand and do not cease to multiply. New Yorkers have sadly become accustomed to what was once a novelty for the city. By now, most people have lost close friends, neighbors and family members to the epidemic and the entire city faces losses that were earlier an almost exclusive experience of the gay community. Drained by losses and by the "trivialization" of living with the epidemic, grass-root movements no longer shake the streets. Radical changes do not seem likely: scientific research can better be described as in a phase of "normal" than of "revolutionary" science (Kuhn 1962). International meetings are no longer annual.

No matter how much the present state of AIDS research can be described as "normality," it carries the fundamental

marks of the social movement. Commentator Bruce Nussbaum numbers the achievements:

The changes in trial design, the beginning of parallel track, the curbing of placebos, the use of surrogate markers instead of death in tests, the quick testing of drugs at the community level, are all revolutionary research initiatives (Nussbaum 1990:332)

Nussbaum analyzes these achievements as things that should have been done long ago; in his view, the reason why better knowledge about AIDS was not available earlier lies in the lack of accountability of today's medical research.

ACT UP, the CRI, Project Inform, AmFAR have consistently shown over the recent years that people with the disease, their doctors, and their advocates know more about treatment than do ivory-tower PIs hidden away from the realities of life and driven by careers that don't reward them for furthering public health (Nussbaum 1990:332)

Like other journalists covering the epidemic (e.g. Burkett 1995, Lapierre 1990), Nussbaum has a volunteer-individualistic view of history, emphasizing the role of characters and personalities in the course of events. My approach is different: even though I mentioned some of the individual actors that intervened in the history of the social movement against AIDS, I have tried to give the social background and elements that allow for a social interpretation of the events.

The shift in the social actors involved in the production of medical knowledge changed the direction of

research; the meaning of this shift to our discussion on the social construction of knowledge will be examined in the last chapter, after adding a number of wider elements into the analysis.

Somehow, and to raise now a topic that will be developed later on, it is possible to argue that AIDS action developed more than just prevention and therapeutic knowledge: the community and their physicians advanced the possibility of a new paradigm for thinking and acting upon on infectious disease. While the scientific community works and thinks accordingly to the dominant paradigm in immunology and infectious disease, which is one of war, military actions and counteractions, defenses and bullets (see Haraway 1992, Martin 1994), the community, without theorizing, developed the possibility of an alternative one -- one that did not develop its full imagery, symbols and language, but underlies the attempts to remain alive in an environment of multiple infections and keeping healthy while overcoming them and keeping them aside.

Chapter 3

SPONSORING GLOBAL ACTION: THE ROLE OF WHO

In the analysis of AIDS activism and its impact on the production of knowledge (chapter 2) I argued that the characteristics of the social movement responding to the epidemic in the United States were closely intertwined with the political culture of this society. That included, among other elements, the history of the fight for civil rights and the consequent expression of individual and group rights, the praise for individual freedom, the feminist health movement, the gay rights movement, and an emphasis on self- and community empowerment. Under these circumstances, the diverse social movements that arose in response to AIDS throughout the world and in many different political cultures should be examined not as replicas or counterparts of the original U.S. AIDS activism, but seen within the context of global action against AIDS and in close relation to the sponsoring of responses to AIDS by international agencies.

Some of the experts involved in those agencies raise similar questions. In the comprehensive **Global Report: AIDS in the World**, editors Jonathan Mann, Daniel Tarantola and Thomas Netter ask whether the patient-based activism on

AIDS is a specifically U.S. phenomenon or whether it became legitimately international (see Mann et al. 1992:231). In fact, there are social responses to the epidemic everywhere, regardless of the fact that the local socio-political characteristics may diverge substantially from those described for the United States.

I will argue in this chapter that the generalized spread of social movements responding to AIDS throughout the world, particularly in the developing countries, is intrinsically connected to its global sponsorship by WHO. This agency was itself influenced at some level by the U.S. social movement against AIDS and marked its special program with the emphasis on human rights and social issues.

In the coming chapters, I will support the argument with a detailed analysis of Brazilian local responses to the epidemic. Brazil provides an interesting example to study the impact of global action because it combines an epidemiology of AIDS which is apparently similar to that of the United States (e.g. Mann et al. 1992) with a very different political culture, one that ultimately challenges the very terms of the epidemiological profile of AIDS (see Daniel 1985, Ramos 1990).

Like most of Latin America, Brazil was subject to Catholic Iberian colonialism since the 16th century. Its economy depended largely on gold mining and on the slave-based plantation system, the root of a social

stratification that remains until our days. This is more visible in the sugar-cane areas of the northeast, from Pernambuco to Bahia, but marks the entire society and culture, including its traditional capital, Rio de Janeiro. The southern states, including São Paulo, more recently settled by the small entrepreneurship of European migrants after the country's political independence (1822), are less stratified as have higher economic development indicators. When Rio de Janeiro became the capital of a colonial empire in 1807, due to the Portuguese kingdom's fear of the republican wave that swept Europe after the French revolution in 1789, political independence became irreversible, even though the country remained in a tight economic dependency in a complex, colonial and post-colonial world-system. Universal citizenship and democracy remained therefore fragile and often interrupted projects. After decades of monarchy, attempts to create democratic structures were brief interspaces within larger periods of republican populism and, like in other Latin American countries, military dictatorship.

Under those circumstances, it is not surprising that the North American style of civil rights and notions of individual self-empowerment are quite remote, at least for the majority of the population. This element will emerge from the analysis of responses to AIDS in Brazil, as it would probably emerge in other social contexts where

individual civil rights are beyond reach and personal or community empowerment are alien concepts. However, as the AIDS social movement in Brazil and the epidemic itself coincided with the end of a military regime that had lasted for two decades, the fight for general civil rights and citizenship that marked local social movements in the 1980s became closely intertwined with organizational responses to the epidemic.

In Brazil, as in many other settings, the bulk of responses to AIDS, from the government to the grass-roots level, coincided with internationally sponsored efforts to promote a global action against AIDS. Sponsors included the World Health Organization, several donor agencies from the developed countries, and international coalitions involving people from developed and developing nations. Funding and sponsored actions became strongly linked to the strengthening of responses to AIDS throughout the world, and global sponsorship helped shape the ways of local responses.

This chapter focuses on the role of the World Health Organization in defining global strategies, awareness, and action involving the different partners affected or seemingly unaffected by the epidemic: developed and developing countries, governments and non-governmental organizations, scientists and the public. The question is whether this scenario of global efforts and new

partnerships provides the fermenting hybridization needed for innovation, as framed in chapter 1. The particular case of fermenting interactions between community and science agencies was the topic of chapter 2; now, I will address the creative power of the new, world-level partnerships.

Although the United States remained the country with the highest number of AIDS cases, over 300,000 of a total of 850,000 worldwide cases in 1993,⁵² most of them occurring in New York City and urban California, it became increasingly clear that AIDS was not just an urban gay disease of developed countries. It affected the entire world, and became known as a **global pandemic** (Fleming et al. 1988, Mann et al. 1988, Mann et al. 1992, Panos 1989, 1990, Sabatier 1988, WHO 1985a, 1985b, 1988b, 1988c, 1989a, 1989b, 1989c, 1992, 1993c, 1994b). With varying effects from region to region, and a complex toll in the developing countries (see Dazinger 1994, Dhillon and Philip 1994, Heise and Elias 1995, Panos 1990, Rothermel 1988, Weill et

⁵²More precisely, the U.S. had 339,250 reported cases of AIDS in 1993, which is about 40% of the 851,628 world total of reported cases at the time (source: **Weekly Epidemiological Record**, January 14 1994). It should be noted that differences in reporting patterns are a biasing element in the portrait of the epidemic's distribution in the world.

al 1994, WHO 1994b), the evaluation of the global impact of AIDS is one of dismay and frustration.

The World Health Organization estimates that the number of new HIV infections on every single day ascends to 5,000 (WHO 1993c:99). For the year 2,000, the projected number of infections varies from 30-40 million in WHO's estimation (WHO 1992:7, 1994b:9), to 38-110 million in the estimation of the Global AIDS Policies Coalition (Mann et al. 1992:107). Despite disagreements over the quantitative methods used in the projections,⁵³ both agencies stress the catastrophic character of the epidemic and its burden on the developing countries -- who, according to WHO, will account for 90% of the HIV infections estimated for the year 2,000.

Besides projections, which serve not only to plan ahead but also to raise awareness, persuade the different countries to develop and improve AIDS programs, pressure the populations at risk to adopt preventive behavior, and lobby the donor agencies to give funds for AIDS, there are

⁵³As a free-lance reporter for the 8th International Conference on AIDS held in Amsterdam, 1992, I observed a not very friendly exchange of words between Michael Merson, then the coordinator of the Global Programme on AIDS, and Jonathan Mann, its former coordinator, who was at the time head of the Global AIDS Policy Coalition. GPA's leader seemed appalled and surprised by what he considered an exaggerated projection of cases by the Global Coalition; this agency had chosen the Delphi method for projections (Mann et al. 1992:106-107) in order to make the estimates for the future.

figures that describe the current situation. In 1993, WHO counted a total of 850,000 cases of AIDS reported by more than 180 countries. With the problems surrounding this disease -- from stigma to the difficulties of diagnosis in countries where there is a high mortality rate -- the agency believes that the actual number of current AIDS cases in the world is over three million (WHO 1994b:17).

As for the number of HIV infections, whether they turned into full blown reported or unreported AIDS cases, or remained asymptomatic, knowingly or unknowingly, the estimate for 1993 is about 15 million accumulated cases of infected persons, of which one million refers to children. About twelve million of the accumulated total cases of HIV infections are alive (WHO 1994b:17).

Geographically, the distribution of the epidemic is uneven. About one million infections are in North America, and another million or more are from South America and the Caribbean. Europe shares 500,000 of the infections, and North Africa and the Middle East about 30,000. Sub-Saharan Africa has the largest portion, estimated in 6,5 million. While East and Central Asia have an estimate of 20,000 infections each, and Australia about 30,000, South and Southeast Asia have the high estimate number of one million HIV infections (WHO 1993c:3). In WHO's words, Southeast Asia current situation parallels that of Sub-Saharan Africa in the early 1980s (WHO 1992:7), and the predictions

for that region are grim unless efficient measures are taken.

Making a more sophisticated analysis of the epidemiologic patterns, the **Global AIDS Policies Coalition**⁵⁴ defined the new concept of "Geographic Areas of Affinity" (GAA). These areas have internal consistency and share common characteristics (Mann et al. 1992:19). Ten areas constitute the "New Global Geography of AIDS": North America, Western Europe, Oceania, Latin America, Sub-Saharan Africa, the Caribbean, Eastern Europe, South and East Mediterranean, North and East Asia, and Southeast Asia (including India). Indexes used by the researchers to characterize the epidemic in each area included: the estimated year of HIV spread (1977-78 for Sub-Saharan Africa, 1978 for North America and Western Europe, 1978-79 for Latin America, 1979 for the Caribbean and Oceania, 1982 to 1984 in the remaining areas); the year of the first diagnosed AIDS case (the early 1980s for the Americas, Europe, the Caribbean and Northeast Asia, the mid 1980s for Sub-Saharan Africa, Southeast Asia, and Oceania, and the late 1980s for the South and East Mediterranean); the availability of AIDS/HIV data; major modes of transmission;

⁵⁴The **Global AIDS Policies Coalition** is a not-for-profit partnership formed by personalities involved in the fight against AIDS at a global level. It was formed and led by Jonathan Mann after he left the coordination of WHO's Global Programme on AIDS in 1991.

urban/rural distribution of cases; the seroprevalence of HIV; the gender ratio (this ranges from ten male cases for every one female case in Eastern Europe to a 1:1 ratio in Sub-Saharan Africa, with the intermediate ratios of 4:1 in Latin America and 8:1 in North America); additional operational data, such as the first year of national response,⁵⁵ the level of external funding (low everywhere except in Africa and SE Asia), and the percentage of GNP spent on health services; and a number of socio-economic and developmental indicators, used by the UNDP, such as the human development index, the total female score, the human freedom index, and the growth rate of urban population annual (Mann et al. 1992:20-21).

Using the Delphi method to calculate the number of infections in the different geographic areas, estimates in the Coalition's Global Report vary from those of WHO. In 1992, according to the **Report**, there was an accumulated number of 12,875,450 infected adults and children throughout the world (Mann et al. 1992:30), of which the largest number are in Sub-Saharan Africa, with 8,770,000 infections, or 68% of the total. This area is followed by

⁵⁵Reflecting a mean between the year a national leader first addressed the issue of AIDS and the year of the creation of a national program, the figures are: 1982 for North America, 1984 for Oceania, 1986 for Western Europe, Latin America, Sub-Saharan Africa, North and East Asia, 1987 for the Caribbean and Southeast Asia, and 1989 for Eastern Europe (Mann et al. 1992:20-21).

North America, with 1,180,000 infections (9.2% of the total), Latin America, with 1,040,000 (8.1%), Western Europe, with 730,000, SE Asia, with 700,000, and the Caribbean, with 330,000 (Mann et al 1992:27). Predictions for the future estimate an exponential growth, and it is on the "pace" of growth that WHO and GAPC diverge. Nonetheless, they agree on the pessimistic evaluation of the impact of AIDS on so many aspects of society, demography, economy, and culture. The only positive outcome, many would acknowledge, has been the vitality and creativity of responses to the epidemic. Referring to the creative impact the social movement against AIDS has brought to clinical research and AIDS policies, the editors of the **Report** comment on the global dimensions of AIDS activism:

A logical outcome of the successes of AIDS activism in the industrialized countries (as exemplified by ... ACT UP), will be to connect issues and struggles in the developing and industrialized countries. Thus, while access to AZT was reduced by high prices in the industrialized world, suitable trials and access to AZT, other antiretroviral agents and drugs to treat opportunistic infections are all extremely limited or absent in the developing world. A history of AIDS activism would also include many courageous and creative efforts in communities and countries around the world. Women refusing to continue subservient sexual roles, community groups working for human rights and dignity, groups working to permit sex education in schools, and people with HIV and AIDS fighting discrimination -- all are activists. Their collective story needs to be documented and told. It is a global story which is making global history. (Mann et al. 1992:240)

Signs of a social breakthrough appear in the midst of the global devastation caused by the epidemic and the dark predictions for its future. WHO tried to bring the world together; it mediated the interactions between centers and peripheries, making a point of giving voice to the generally silenced peripheries. Within the realm of the global fight against AIDS, WHO and other international agencies helped creating a worldwide infrastructure for easier and affordable telecommunications. Fax-machines and modems enabling easy access to electronic mail and bulletin board services were made available almost everywhere, making the circulation of information much less expensive. Travel funds were also made available, and those whose lives were confined to peripheries got acquainted with the centers of decision; their voices became more audible through a number of electronic and printed media, as well as real life conferences and meetings.

For us, the question is whether this new apparatus created the material possibility for a dramatic change in the center-periphery interactions, or whether it just brought a new outlook to the previous hierarchical order of things. The process of science-making is usually portrayed as a hierarchical polarity between the "first" and "third" worlds, whether in a "modernization" or a "dependency" model (see chapter 1). A more interactive scenario would be a radical change from that order of things; would that

ideal global setting be the locus of a paradigm shift in the biological sciences, as referred in chapter 1? Global interactions might be as fertile a scenario for the creation of new knowledge as the activists interaction with the science agencies in the United States were (see chapter 2).

Brazil seemed an ideal site to investigate this problem due to the vitality of local medical research. Both the field of immunology and the field of social epidemiology, not to mention clinical practice in "tropical" infectious diseases and the strong tradition of studying the social dimensions of medical problems, gave enough possibilities for a creative and fertile interaction of models that might improve the field of knowledge about AIDS. Before going into local details, though, we should examine the conditions of the global sponsorship of a change in the field of AIDS.

The fact that the international AIDS movement sponsored by WHO from 1985-86 generated a transformation throughout the world is documented in several newsletters and world reports, including: **Global AIDS News**, a newsletter of the Global Programme on AIDS; **Aids Health Promotion EXCHANGES**, a newsletter jointly edited by the GPA

and the Royal Tropical Institute of the Netherlands (KIT), later by this institute alone, and later jointly by KIT and SAlAIDS, the Southern Africa AIDS Information Dissemination Service located in Harare, Zimbabwe; **AIDS Action**, published by the London-Based AHRTAG (Appropriate Health Resources and Technologies Action Group) in different languages; and collective volumes like the series edited by the Panos Institute (Panos 1989, 1990, Sabatier 1988); the comprehensive **Global Report: AIDS in the World** (Mann et al. 1992), or WHO's **AIDS: Images of the epidemic** (WHO 1994b); and a number of local publications such as, to quote the Brazilian and best known ones, **Boletim ABIA** and **Cadernos Pela VIDDA**. Also, the number of government documents on AIDS published throughout the world after 1988 signals the influence of WHO, as they attempt to build up programs that follow the guidelines of the agency.

The circulation of AIDS information through these publications evidences changes in the world of knowledge dissemination, if not in the process of knowledge making altogether. A judgment of its impact on the world of science involves further examination. At a formal level, there are visible transformations in the relations between different disciplines in the context of AIDS. Traditionally, medical knowledge travels from research specialities to the clinical sphere and from there to the social sphere, not the other way around. Clinicians use the

knowledge of virologists, for example, and social workers use the knowledge of clinicians. AIDS newsletters permitted a circulation of information in the opposite direction, making available to biological researchers the knowledge of community-based organizations. Also, the format adopted by the main forums for knowledge on AIDS had a very special, interactive character.

Those forums, the **International Conferences on AIDS**, were truly interdisciplinary meetings that brought together different disciplines for intense dialogue; they included the participation of PWAs, community organizations, plus significant representation by the developing countries (see Bastos 1992). The format of the conferences did not replicate traditional medical forums, where interdisciplinary dialogue badly extends beyond contact between basic researchers and clinicians. In the AIDS conferences there were clinicians, basic researchers, epidemiologists, social workers, social scientists, activists of different sorts, pharmaceutical industries, governments, non-profit organizations, traditional healers -- a rainbow of diversity that sometimes made the traditional scientists nostalgic for the single-discipline forums. The big AIDS conferences were just different from anything that existed before: they had incorporated the double impact of AIDS activism and global sponsorship.

A further question concerns the impact of the global fight against AIDS on the traditional hierarchies within

disciplines. By giving particular attention to the voices of the Third World, WHO's action had an effect on transnational scientific communities. Traditionally, and under the assumption of the modernization and dependency paradigms, audibility is directly proportional to the developmental status of the local scientific community within the international system. Central, industrialized countries are the producers of legitimate knowledge; peripheral countries consume it or, at the most, adapt it for local use. They are not assigned to produce mainstream knowledge. However, under the innovations and transformations brought by the fight against AIDS, the "silent" patient inverted the hierarchy of knowledge (and power) with the doctors and the medical establishment (see chapter 2). Would anything similar happen to the central/periphery hierarchies in science? Did the impact of the global action against AIDS reverse the hierarchies, bringing research ideas and findings from the developing countries into the mainstream? Did the new international partnerships created to fight against AIDS represent the fertile cross-fertilization for the generation of breakthrough research? And if so, did they reverse the traditionally top-down, north-south, center-periphery direction of knowledge-dissemination? Was the developing world participating actively in a process that mattered for the world in general, and most of all for the developing

world?

Following the rhetoric of WHO, and focusing on aspects like the audibility of developing countries in international forums and newsletters, one might think that a real transformation was on its way in the context of global action on AIDS. If that were true, it might mean that the structures of dependency were being replaced by dialogical interactions and global communication. I risk saying that the experience of participating in the global fight against AIDS during a brief period of time, particularly in the years 1989-1990, brought to many a taste of that utopian possibility.⁵⁶ It was also the time of "utopian treatment activism" (Harrington 1992) in the United States, the brief period of social opening that followed the cold war, and a hard to match moment of social optimism. The world seemed to be undergoing enormous transformations. There were visible effects of the new partnerships and global action in the shape of social

⁵⁶Evidence for this statement comes from a long period of observation of the AIDS international movement (1988 to present), which included: participation in the alternative conferences during the Sixth international conference on AIDS in San Francisco, 1990; participation in the Seventh, Eight and Ninth conferences in AIDS in Florence, Amsterdam and Berlin as an observer and as a journalist; interaction with AIDS activists and AIDS program officers from North and South America, Europe and Africa, members from international AIDS networks, and WHO officers; interviews focusing on the AIDS international movement; close observation of AIDS activism in New York and Rio de Janeiro.

responses and the development of community programs (see As Sy 1995, Cash et al. 1994, Filgueiras 1994, Kit and SAfAIDS 1995, Mussauer 1994, Rowe 1994). This chapter will show the close interdependence of the local and global levels of action and decision making; subsequent chapters will take a perspective from a local setting, Brazil, and will be followed by an analysis which also involves the field of biomedicine.

For now, I will address the local/global interdependence taking a perspective from the global sponsorship of WHO; the understanding that AIDS affected the developing world had an impact on the agency's decisions and was followed by the implementation of a global action program.

The First International Conference on AIDS, held in 1985 in Atlanta, Georgia, also the home of the Centers for Disease Control, was not the average scientific forum. The disease was considered a mystery whose causes were poorly known. The isolation of LAV/HTLV-III had less than a year, and the relevant information changed so rapidly that a thorough review of knowledge was needed (WHO 1985a:98). For that purpose, more than 2,000 people from 50 countries met in Atlanta (WHO 1985a:99). The event has been repeated

every year with a growing audience, participation and social visibility.⁵⁷

From the very beginning, AIDS was not a regular disease with predictable research problems. Such uniqueness refers not only to the biology of HIV and AIDS (WHO 1985b:207), its epidemiology, and its politicization in the developed urban centers (chapter 2), but also to its worldwide dimensions and the complexity of the related interactions.

By 1985 it was already evident that the epidemic had far more implications than its already complicated characterization as an urban gay disease. Right from the beginning, in the United States AIDS evoked male homosexuality, but from a European-based international perspective it evoked Africa. "Africa" was not then the

⁵⁷The conference became annual and was repeated with an alternation of American and European sites: in Paris, France, 1986; Washington D.C., 1987; Stockholm, Sweden, 1988; Montreal, Canada, 1989; San Francisco, California, 1990; Florence, Italy, 1991; in 1992 it was planned for Cambridge, Massachusetts, but due to the organizers' opposition to the U.S. restrictions on the entry of people with AIDS, the conference was transferred to Amsterdam, Holland. In 1993 it took place in Berlin, Germany, and, in 1994, Yokohama, Japan, was the first Asian site to host the conference. Since research on AIDS entered a phase of "normal science", with more predictable results, the number of novelties per year is no longer considered worth the effort of gathering thousands at the expensive mega-conference, which became bi-annual; Vancouver will host the 1996 conference. Also, smaller and specialized meetings are now the preferred sites for the exchange of knowledge within the AIDS subdisciplines, and most of the achievements in information can be exchanged worldwide through the new communication technologies.

symbol of exoticism and remote origins it became later in other contexts; it represented the harsh reality of Africans getting sick in significant numbers. Many of the former colonial institutes of tropical medicine located in Europe regularly assisted cases of severe infectious diseases brought from Africa by migrants and visitors; most of the early AIDS patients were either African or had been in Africa; an African link was what seemed most plausible to the French researchers involved with the initial identification of LAV. American reporter Randy Shilts describes the AIDS situation in Europe as of two epidemics, the first one linked to Africa and the second linked to U.S. gays (Shilts 1987:261). Back then, however, the idea of AIDS as an African disease was as odd to Americans as it being a gay disease was for most Europeans or Africans.⁵⁸

The evidence from Africa showed that the epidemic had been devastating large parts of the continent for longer than it had affected North American gay communities. African epidemic clusters⁵⁹ were different from those in

⁵⁸Both ideas overlapped and interacted; a conceptual middle ground had to be reached. The definition of two epidemic patterns, which will be described later, partly resolves the opposition.

⁵⁹My first acquaintance with the global data on AIDS was in 1988 through the non-trade sheets published by the Panos Institute available at the New York Public Library, later published as the **Panos Dossier** (Panos 1989). Because every page was copyrighted and could not be xeroxed, I had to hand copy the data, which was categorized by country. This made me pay a close attention to the distribution of AIDS reporting in Africa. The very uneven character of its distribution across the continent made me think that social

the U.S. (WHO 1985a:98). However, it took several years before the epidemiology of African AIDS was defined in its own terms, that is, around clusters of roads, traffic, warfare, and other **social** variables. In the initial years the individual-behavior based epidemiology of AIDS in the U.S. served as the reference for identifying and defining the epidemiology of AIDS in Africa and everywhere else. Therefore, in contrast to a predominantly "homosexual" AIDS in America, African AIDS was defined as predominantly "heterosexual," an individual-behavior variable, and not as linked to multiple deprivation, accumulated STDs, poverty, economic depression, continuous warfare, migrations, and even iatrogenic causes, as it would be characterized many

variables like economic development, surveillance mechanisms and maybe international ties related to European colonialism might be influencing the figures. For example, the former Belgian colonies of Rwanda, Burundi and Zaire had the highest incidence of cases. I learned later that some of the researchers most involved with AIDS were from the Belgian tropical medicine institute and had developed lines of cooperation and assistance with the former colonies, a fact that is also noted by Shilts (1987:392) and Garrett (1994). Also, former Portuguese colonies like Angola, Mozambique, Cape Verde and Guine Bissau, scattered across the continent, had cases of HIV-2 when this virus seemed to be confined to West Africa. I learned later that HIV-2 had been isolated for the first time in Lisbon, Portugal, in cooperation with the Pasteur Institute HIV team; researcher Odette Ferreira pursued the analyses of blood samples of a number of AIDS patients from the tropical disease wards of Egas Moniz hospital, who repeatedly tested negative for the then available HIV tests. The influence of other variables, like war, traffic, and migrations, became increasingly clear as social researchers contributed to the study of AIDS in Africa.

years later (Baldo and Cabral 1991, Garrett 1994, Mann et al. 1992, Packard and Epstein 1991, Preston 1994, Schoepf 1991).

For years, African AIDS was reified as heterosexual in the same way that American AIDS had been reified as homosexual, regardless of its internal diversities. That the U.S. "homosexual" characterization of AIDS constructed the "heterosexual" characterization of African AIDS, providing a dual-choice model for the rest of the world, is a clear example of how epidemiology draws on local social constructions and historicized categories; it further shows that the process of the global characterization of the epidemic was asymmetrical and one-sided, treating a particular local knowledge (of the 1980s U.S.) as universal.

AIDS might have not started in America (e.g. Gould 1993) but it was there that it had its "cognitive birth," a fact that at the same time spared time and lives (Mann et al. 1992) and marked the understanding of the epidemic forever. The "search for origins" helped make it visible everywhere, including in the developing countries where AIDS blended with many other pre-"epidemiological transition" ills and premature death. The "retrospective," North-South tracking of the epidemic globalized and apparently unified the world under a common problem: all shared the new epidemic. However, this unification was only

a partial one. It took the level of individual behavior as the relevant variable to define epidemiology and epidemiologic patterns, and it perpetuated a dual pattern model (I/II) that only replicated the opposition of developed and developing nations, or of first and third world. The reference to define the epidemic pattern for AIDS in any country, and, as we will see in the next chapter, in Brazil in particular, became that of an "American" epidemic or an "African" one, as if doubling the opposition of development and underdevelopment.

Knowledge about the diversity of forms the epidemic assumed throughout the world was made static under the frame of WHO reports that described worldwide AIDS as having several different patterns (Mann et al. 1988:84). Pattern I corresponded to the developed countries, and was characterized by a main quota of infections by homosexual transmission, plus some intravenous drug transmission. Pattern II was characterized by mainly heterosexual transmission, and corresponded to Africa and the Caribbean.⁶⁰ Pattern III corresponded to the countries with low reporting. The contrast pattern I/pattern II clearly mirrored the contrast between nations that were

⁶⁰The popular/media version of this association not only drew on stereotypes of reckless black sexuality but also incorporated several exoticisms (circumcision, clitoridectomy, scarification) as the ways of transmission for African AIDS.

characterized in terms of post-epidemiological transition and those who were in pre-epidemiological transition. This bi-polar model framed the minds of epidemiologists, clinicians, basic researchers, activists and policy makers throughout the world for many years.

Interestingly enough, it was in Brazil that a number of voices challenged this partition of the world epidemic. Political writer and later AIDS activist Herbert Daniel challenged, from the very beginning of his public action, the use of the established biomedical and epidemiological models, in which he was followed by other public writers and social scientists (Daniel 1985, 1989, Daniel and Parker 1990, Guimarães et al. 1988, Ramos 1990, 1992), mostly connected to ABIA (see chapter 4). The influence of ABIA in the AIDS-NGO movement in Brazil, as well as the consonance of activists like Daniel and the other engaged scholars with the emerging social movement, partly explains the recurrent resistance of Brazilian activists to being placed in the traditional epidemiological categories. Time and again, newsletters from Brazilian NGOs challenged the use, by the government, of the "imported models" of epidemiology (see ABIA 1988b, 1988c, Daniel 1985, 1989, Guimarães et al. 1988, Ramos 1990), and refused to classify the epidemic in Brazil as under the pre-defined pattern I or pattern II. Brazil had a specific epidemiology, they argued, and the very terms of it should be a priority for research. To see

it through "imported models" and "imported categories" would only create an artificial understanding of the epidemic in Brazil -- a fact that activists accused the government and the media of doing constantly. In order to expose the mechanisms that build such distorted understanding of the epidemic, a group of researchers, with two anthropologists and a political activist, engaged in de-constructing the use of the standard categories applied by doctors reporting AIDS cases by examining the files of the first 200 cases reported in Rio (Guimarães et al. 1988). They concluded that the official epidemiological categories, focused on the identification of "risk-groups," were inadequate for local culture⁶¹ and helped concealing the actual face of the epidemic in Brazil (see Guimarães et al. 1988), whose specific characteristics should be researched in the first place, a task that ABIA included as a priority on its agenda (see chapter 4).

Coinciding with those local views, the work of anthropologist Richard Parker (1987, 1988, 1991a) in Brazilian sexual culture stressed its specificity, based on cultural elements like the fluidity of categories and the permanent transgression. In his argument, Brazilian sexual ways were irreducible to the categories used by

⁶¹Definition of risk was as odd as to emphasize the category "travels to Haiti" in the questionnaires given to possible cases of AIDS.

international agencies, which were derived from contemporary North American culture and focused on the distinct opposition between homosexuals and heterosexuals.⁶² Later on, more anthropologists argued similar points for other Latin American sexual cultures (Carrier, Lancaster 1994, Murray 1995).

Parker argued that those points were extremely important regarding AIDS prevention policies. Rather than presumed as equal to anywhere else, local sexual ways should be investigated and its knowledge should be at the basis of any local AIDS policy. Brazil was an illustration for the argument, which should be valid for most of the different cultures of the world. Parker's work had a significant, if temporary, influence in global agencies (e.g. Parker and Carballo 1990, 1991, Parker, Herdt and Carballo 1991), and the author turned himself into a international broker and often the official voice of the social-behavioral component of AIDS research within global networks.

⁶²The critique was not shared by everyone. Self-acknowledge gay groups, even though small in number and clientele, accepted the U.S. model. So did the government, and epidemiologists that entered the AIDS research bandwagon. Most medical doctors, even though recognizing the possibility of a number of special characteristics on Brazilian sexuality, did not challenge the mainstream model, which actually coincided with their own medical training. In 1991, the media speculated grandly about the possible "Africanization" of Brazilian AIDS, meaning that predominantly homosexual transmission was being replaced by predominantly heterosexual transmission.

Not independently of the local efforts for the revision of mechanic categories and strict epidemiologic patterns, the authors of the **Global Report: AIDS in the World** (Mann et al, 1992), which is dedicated to the memory of Herbert Daniel, depart from the original 3-pattern classification developed by some of them while at the WHO (Mann et al 1988). They update the global epidemiology of AIDS into a 10-categories frame of "Geographic Areas of Affinity" (Mann et al. 1992).

WHO cherished the concept **global** and applied it to health problems long before it became a perishable buzzword in sociology in the late eighties and early nineties (e.g. Albrow and King 1990, Bergensen 1990, Featherstone 1990, Featherstone, Lash and Robertson 1995, Friedman 1994, Hannerz 1992, Ianni 1992, King 1991, Robertson 1992), and before it became a pet expression for corporate business (e.g. Barnett and Cavanagh 1994). The agency's introductory publication **Fighting Disease** phrased its take on mass disease as "a global approach to global problems" (WHO 1962:30). The global problems were tuberculosis and malaria, which still ravaged the populations of the Third World while Europe and North America were in their "baby boom" years of demographic expansion, economic growth, and

social development. The program created later to develop research in tropical disease was conceived as a "global partnership" (WHO 1987).

Like the other agencies of the United Nations, WHO had been created in the spirit of optimism and initiatives for cooperation that characterized the post-World War II era (see National Health... 1993, WHO 1962, 1975, 1976, 1988a). Global by definition, covering the entire globe, inheritor of the **Office International d'Hygiene Publique**,⁶³ WHO lived its first decades under the optimism of growth and progress that characterized the 1950s, 60s and 70s. Its success in the eradication of smallpox, another "global programme" (WHO 1976:18) helped consolidate the idea that it might be possible to defeat disease worldwide. Social scientist J. Peabody (1995) argues that the success against smallpox increased the pressure on WHO to eradicate other ills that ravaged the Third World. Medical writer Laurie Garrett (1992:825) points out the influence of that success on the declining importance of infectious disease in the medical cultures of the developed world. And yet, as this author shows later (Garrett 1992, 1994), this was but an illusion and a far from irreversible episode in medical history.

⁶³Created in 1907 in Paris, O.I.H.P. was the first agency to address the problems of international health. WHO followed the refugees of war commission and started activities in 1948.

Under the one-nation-one-vote World Health Assembly, WHO's main constituency was clearly that of the developing countries, even though most of the agency's funding came from the few developed countries in the United Nations. As it became apparent that post-war economic development did not generate equal or even proportional benefits for all, but rather increased the webs of dependency and unequal development, Third World health problems became a primary target for the agency. Africa was somehow the very embodiment of the Third World, its problems aggravated by the effects of recent and late colonialism and split nationalities. Responding to the African famine/drought crisis and its health implications, **WHO Chronicle** reported that

the crisis that Africa continues to face is not purely one of recurrent drought or famine; it is a **development** crisis affecting all fields of endeavour, including food and other rural production incentives, social planing and gradual alleviation of the unfavourable socioeconomic conditions that prevail throughout most Africa (WHO 1986c:234).

WHO's original definition of health, not only as the absence of disease but as general physical, mental and social well-being, required more than just giving out medicines to kill microbes and vaccine shots to prevent them. It needed, in the agency's words, global efforts and

global strategies. In the seventies these efforts were crystallized in the project "Health for All by the Year 2,000" (Torino and Creese 1990, WHO 1979, 1980, 1981, 1986a, 1993a, 1993b), which seems now so over-optimistic, given current world health trends in AIDS, tuberculosis, malnutrition, infant mortality, and the quality of drinking water (WHO 1994a). In his organizational analysis of WHO, Peabody describes the "Health for All" goal as "vague," "utopian," and "unreachable" (Peabody 1995:735).

Following the 30th World Health Assembly (1977) and the International Conference on Primary Health Care in Alma-Ata (1978), the principles of "health for all" became the driving force of the agency. In 1981 the "Global Strategy for Health for All by the Year 2,000" was adopted by the Health Assembly (WHO 1994a:15). "Global" seemed the agency's favorite concept: there were "global strategies" and "global policy for health" (WHO 1979:40), "global promotion and support" (1979:41), "global information exchange" (1979:42), "global orientation and support for research" and "global use of national expertise (1979:43), as well as "global monitoring and evaluation" (1979:44), "global level," "global coordination," "global enlistment" (WHO 1981:86), "global promotion and coordination of research and development" (1981:87), "global advisory committee on medical research (WHO Chronicle 37(1983):4), "global partnership" (WHO 987), and "global policy framework" (WHO 1994a:15).

Against this background, the scope of an international epidemic with the characteristics of AIDS became WHO's major concern. Anticipated by a meeting in 1983 held in Geneva to appraise the problem, WHO's "earnest involvement" (WHO 1986b:52) with the new epidemic started with the First International Conference on AIDS in Atlanta, 1985, with the WHO Consultation on AIDS and EURO Consultation on AIDS (WHO 1985b:211). Later that year, in October, the agency organized the first meetings on AIDS in Africa, in Bangui, in the Central African Republic. Besides Central Africans and WHO officers, there were participants from Rwanda, Burundi, Uganda, Tanzania, Zaire, Cameroon, and Gabon; the aim of the meeting was to establish cooperation for data-gathering in those deprived areas (WHO 1985b:211). As for other regions, in December 1985 WHO's American branch PAHO, the Pan American Health Organization, had created the working group on AIDS Guidelines; by the end of the year there was another WHO AIDS conference in New Delhi, India.

A few other AIDS-related scientific meetings were sponsored that same year: the WHO informal meeting on T-lymphotropic Retroviruses of Non-Human Primates, Geneva, July 85; the Scientific Group on Non-A Non-B Hepatitis, Delta Antigen-Associated Hepatitis⁶⁴ and Blood-Borne Human Retroviruses, in Tokyo, October 85; the Consultation on

⁶⁴Those are known, now, as hepatitis C and Delta.

AIDS -- Safety of Blood and Blood Products, Geneva, December 1985; the Second Meeting on Simian Retroviruses, also in Geneva, December. Moreover, there were two meetings of the "WHO Collaborating Centres on AIDS," in September and December. The pre-existing structure of collaborating centers and the related networks constituted the infrastructure after which WHO could rapidly create the global program on AIDS and a system of monitoring the epidemic as well as responding to it at the level of the entire planet. The initial program included

the exchange of information, the preparation and distribution of guidelines and educational material, support for laboratory diagnosis, cooperation in the development of national programmes and action of AIDS containment, advice on the provision of safe blood and blood products, and the coordination of research. (WHO 1986b:52)

Even though it had already been working informally, the **Special Programme on AIDS** was officially established on February 1st 1987, invested with the "responsibility for the urgent mobilization of national and international efforts and resources for Global AIDS prevention and Control" (WHO 1988b:2). The AIDS epidemic was defined as a "world health problem of extraordinary scale and extreme urgency," representing "an unprecedented challenge to the public health services of the world" (WHO 1988c:1).

The **Global AIDS Strategy** was endorsed unanimously by the World Health Assembly in May 1987 (WHO 1992:19,

1994b:4), presented to the Venice Summit of Heads of State and Government in June of that year (WHO 1992:19), and formally adopted by the United Nations General Assembly in September 1987 (WHO 1992:19, 1994a:4). In January 1988, it was presented to the World Summit of Ministers of Health and Programmes for AIDS Prevention in London, resulting in an early state-of-the-art compilation of papers (WHO 1988b).

The **Special Programme on AIDS**, later the **Global Programme on AIDS**, made a point of involving the developing countries, and Africa in particular, in the fight against AIDS. The fact that by 1985 over 90% of the reported AIDS cases had come from the United States and Europe (WHO 1985b:211) was interpreted by the agency not at face value, but as hiding the asymmetries in systems of reporting:

neither the overall number of cases reported nor their countries of origin present a true picture of the epidemiology of AIDS, since there are vast differences between countries in funds and other sources available for the surveillance of disease. (WHO 1985b:211)

For our analysis, the lines that follow are the most interesting: WHO states the hope that a collaboration with the developing countries may bring a significant contribution to the advance of knowledge about the epidemic:

It is our hope that the mechanism established by WHO for international surveillance will yield a more

complete picture of AIDS and hasten the progress towards solving its more profound mysteries (WHO 1985b:211)

That a knowledge breakthrough was expected from the involvement of the Third World seems to be demonstrated; whether this breakthrough could be extended beyond epidemiology and community action and into clinical and basic science required additional expectations (see Mann 1991). The field with the most intense and visible new interactions and multidirectional flows of information was the area of prevention, which counted on the involvement of local organizations; this is also the area that receives the most attention in the world newsletters mentioned above (e.g. As Sy 1995, Cash et al. 1994, Filgueiras 1994, Kit and SAfAIDS 1995, Mussauer 1994, Rowe 1994).

A significant amount of the funding and expertise provided by WHO was channeled not only into the implementation of national programs on AIDS but also into community-based organizations. There was too little time and too many lives at stake in this complex problem to overlook any possible action, even if was to be unconventional. With the impact of the AIDS epidemic, the entire project of "Health for All By The Year 2,000" was bound to collapse prematurely. Following the successful example of U.S. community-based strategies to fight AIDS, WHO tried to involve, fund and create community-based organizations throughout the developing world in order to

fight off the epidemic. This included endowing community-based organizations throughout the world with the technological means necessary to maintain a constant interaction with international agencies in order to share information quickly and efficiently. Technological innovations coincided with the popularization of fax machines, micro-computers, CD-roms and electronic networks. Many of these technical devices were explored and developed in their application to AIDS communication and networks.⁶⁵

Under the leadership of Jonathan Mann and a few tireless and sensitive health experts, GPA was a dynamic and innovative agency within WHO (see Garrett 1994:459-465). Mann became quite popular in Third World countries and among community activists; he embodied advocacy for the involvement of the community, respect for human rights, and compassion for people with AIDS. The top level agency and its representative had learned from the grassroots that a problem like AIDS should not be addressed with the regular strict public health measures for epidemics, like quarantine, confinement, and contact tracing in order to separate the sick from the healthy. If it were, that might

⁶⁵Evidence for this statement was provided during field work in Brazil, where I observed the expansion of the Alternex network in 1991, years before the contemporary popularity of the Internet and World Wide Web; the first CD-rom device I ever saw existed in one Brazilian NGO at least as early as 1990; fax machines were a priority for even the smaller NGOs; and all these devices were used profusely.

only deepen the alienation of those at risk, make the epidemic go underground, increase the number of infections, and worsen the already difficult situation of people living with AIDS. It seemed that the agency had learned something new and different from the traditional and hardline public health style, which may have been adopted only in the iron-handed and self-sufficient Cuban regime.⁶⁶ The involvement and engagement of people with AIDS and community organizations became an official policy of WHO, spread around and passed on to donor agencies and local governments.

⁶⁶Reminiscent of the one Pacific island that was able to escape the 1918-1919 influenza pandemic by not allowing anyone in, Cuba was able to maintain the AIDS epidemic under a level of control unattainable in any other country. Traditional public health measures were implemented with widespread testing, contact tracing and quarantine. The cost of these measures in terms of individual human rights was not a main concern for the Cuban regime, whose priorities are in the public sphere. Untransferable to any other political setting, the Cuban model has been condemned by human rights activists throughout the world, praised in solo by anthropologist Nancy Scheper-Hughes (AAA 1995). Human rights activist and WHO consultant Ana Filgueiras, a long supporter of the Cuban regime, after visiting the island for a month and getting acquainted with the situation of PWAs in Cuba and their doctors at the invitation of Cuban Ministry of Health, concluded that the situation is still condemnable from the perspective of human rights, in spite of the high quality of assistance (personal communication, 1992). Oblivious of the individual rights and self-centered narratives, including the impressive account by Cuban exile Reynaldo Arenas (1993), Cuban medical doctors center their action in providing medication, including interferon, as well as good quality housing for the life-quarantine (see Perez et al. 1994).

The guidelines provided by WHO for the development of national AIDS programs in different countries (e.g. WHO 1988c, 1989a, 1989b) were far more progressive than most governments (many of them part of authoritarian regimes) would ever have come up with. The GPA tried to make governments understand the importance of developing a national program and funding it. WHO helped them get the funding, either by lobbying or by providing it directly. Some of the recommendations were hard to implement with funding alone, for cultural and ideological elements were as powerful obstacles as lack of resources. For example, the guidelines spoke candidly about drug abuse and homosexuality (e.g. WHO 1988c), whose existence many governments refused to acknowledge and always considered as a foreign phenomenon. As late as 1985, Japanese medical authorities are quoted dismissing the local relevance of AIDS because they believed there were no homosexuals in Japan (Shilts 1987:156). As late as 1988 Chinese authorities claimed that China had no AIDS cases because homosexuality, promiscuity and drug use are prohibited by Chinese law (Panos 1989:170).

Also, amid the dry language of medical policy, the guidelines included the recommendation to "promote the use of condoms" (WHO 1988c:6). In countries where the Catholic Church held sway this was hardly conceivable, much less

feasible.⁶⁷ The Global Programme tried to persuade the governments of the importance of including people with AIDS and community-based organizations in the design and implementation of the actions. This concept seemed extraordinary to the traditional mentality of public health officers, whose guidelines for epidemics consisted of isolating the sick and protecting the healthy from contamination. Also, many of the activists speaking as people with AIDS were opponents of the ruling authoritarian regimes. For many governments, to include "revolutionary" PWAs as part of anti-AIDS official policies was almost inconceivable. Yet, GPA had discovered the potential of this formula by learning from the action taken by empowered movements, namely in the United States.

It is symptomatic that in one year alone, between the publication of the Guidelines for the Development of a National AIDS Programme (WHO 1988c) and the Guiding principles for monitoring them (WHO 1989a), the role given to people with AIDS in WHO manuals changed substantially. In 1988, people with AIDS were referred to in a small entry as deserving care and compassion:

⁶⁷There are many examples illustrating this point. Even non-Catholic New York suffers the pressure of Catholic Church over the issue of condoms. In Brazil, one of the early campaigns portrayed a woman holding a condom and suggesting **previna-se** (literally, "prevent yourself", or "beware"). The Catholic Church vetoed the poster, which was released without the condom -- and hardly any message.

Because of the psychological and other effects of HIV, those most directly affected (persons already infected, with or without clinical illness), along with their sexual partners, household members, and others in the environment, must be helped with their problems through counseling, education, and other ways. (WHO 1988c:7)

One year later, PWAs were presented as active and necessary partners in the fight against the epidemic:

Their own experience makes individuals with AIDS potentially excellent educators about HIV infection and its consequences. They may be particularly effective as sources of information about aspects of AIDS that is [sic] difficult to convey otherwise or for target audiences that are not easy to reach through conventional information and education programmes. (WHO 1989a:37)

The years of 1989-90 were probably the peak of WHO's globalizing efforts in the fight against AIDS. Connections with Third World countries and activist organizations were a priority for the Global Programme on AIDS. NGOs throughout the world praised Mann's leadership and contributed to the Programme's innovative energy. In countries like Brazil, where both NGOs and the government had strong links with GPA, the restructuring of the Programme in late 1990, which included Jonathan Mann's replacement by Michael Merson, was initially seen as unfortunate.⁶⁸ Even though the new office maintained the

⁶⁸Support to this statement comes from observations and informal conversations with Brazilian NGO leaders as well as community involved doctors in 1991. They do not, however, express the views of the totality of Brazilians, and the new coordinator, even though less flamboyant,

support for NGOs and social action, enthusiasm for the novelty of community participation gave place to a more medicalized and epidemiological approach.

In the following years there was some competition for global leadership of social knowledge and international social action against the epidemic between GPA and the newly formed **Global AIDS Policies Coalition**, coordinated by Jonathan Mann and a number of collaborators based at Harvard and with partnerships with many different countries (see Global AIDS... 1991). The Coalition's visibility and influence peaked in 1991-92 with two major global contributions: the Eighth International Conference on AIDS, organized in 1992 in Amsterdam as an alternative to Boston because of the continued restrictions on HIV-positive travelers to the US; and the publication of the mammoth report **AIDS in the World** (Mann et al. 1992). The book was rapidly translated and published in Brazil (Mann et al. 1993), where the Global Coalition maintained a significant influence (see ABIA 1992, 1993a).

In January 1996, GPA is supposed to be replaced by a larger inter-agencies office in the U.N., the UNAIDS, headed by Peter Piot, who has been associated with AIDS action since the very early years of the epidemic. The

proved to be engaged with the developing countries and Brazil in particular.

creation of an interdepartmental agency has long been demanded by many of the experts and activists involved with AIDS throughout the world (Filgueiras, 1993, personal communication). In order to act on some important fronts, the global programme needed the cooperation of agencies like the World Bank, FAO, UNICEF, UNPD, which were peers rather than subordinates of WHO.

WHO's role in the fight against AIDS is at the end of a cycle. Some analysts venture already an evaluation of that role, which has naturally involved a number of problems. According to J. Peabody, AIDS was treated with a frame that has been used with more or less success for a number of problems, and which he describes as the "Yaws approach" (Peabody 1995:735) and interprets as the organizational culture of WHO. The "Yaws model" is named after the successful 1950s campaign against yaws, a disfiguring infectious disease caused by an agent similar to that of syphilis. The campaign involved international meetings, the training of national staff, and the distribution of technology (Peabody 1995:735,741). "Yaws" became the prototype for other programmes, consisting of "technical meetings, consultative visits, fellowship training, and the provision of supplies" (Peabody 1995:736). In this author's analysis, the model is inadequate to a number of problems, namely those diseases that do not have "magic bullets." In those cases, which

included AIDS, other approaches should be explored (Peabody 1995:741).

In my interpretation, however, there was more to WHO's action toward AIDS than the mechanistic "yaws approach," and particularly so in the first years of the Global Programme on AIDS. As one of the central novelties in the fight against the epidemic, GPA made a point of including the experience of people living with AIDS and their contribution. It also created the conditions for a global awareness and a global approach that reduced the possibilities for hazard and arbitrarities in local action. The staff of the Global Programme on AIDS worked hard for that goal. Mann and his team travelled constantly throughout the world to give visibility to the problem and to show the complexity of the approach required: not a simple medical issue, but one that included its social and political dimensions. In doing so, they created a material infrastructure of communications and a worldwide network of connections that give to the AIDS struggle its "global" outlook: a network of partnerships and interactions that moved fast, communicated easily, and subverted the traditional hierarchies between countries and between disciplines.

Even though WHO had made "global" its key concept and developed a few global programmes for worldwide health problems, the innovative shape and the direction taken by

the fight against AIDS were rather exceptional. As author Laurie Garrett notes, Mann's Global Programme on AIDS shook the Geneva bureaucratic structures and raised envies throughout the organization. The high-profile of GPA and its officers emphasis on human rights as a key issue for action on AIDS generated negative reactions around, including anger and jealousy (see Garret 1994:476,481). The fact that AIDS figures were smaller than many other diseases was used to argue against the special attention to the new epidemic. Hiroshi Nakajima, director of WHO since 1990, tried to adjust GPA to the regular protocol of the agency, while the GPA's officers had already established a style that went much beyond it. The split from WHO divided loyalties throughout the world; and this epidemic, which had raised in so many people and in so many places a type of consciousness that never had taken place before, retreated to a more predictable and frustrating medicalized mode. However, the structures and awareness created during the most active years of GPA had influenced actions and ideas throughout the entire world. It might be that the year of 1990 marked the impossibility of going further in a process that was then foreseen: a process of total dialogue, subverted hierarchies, creative partnerships, and multiple revolutions. But the hopes for general transformation were in the airwaves, and the possibility for change was more than a intellectual projection: it was

the key to continue alive for just too many people.

Chapter 4

LOCAL ACTION: RESPONDING TO AIDS IN BRAZIL

As seen in the previous chapter, in most places outside the U.S., AIDS became an issue before there were any reported local cases. The epidemic acquired an ideological configuration that was somehow independent of its actual course, a fact related to the local perception of AIDS as a foreign disease. In some cases, the new disease was considered a man-made, genocidal device, like a cold war weapon out of control (see Panos 1989, Sabatier 1988); after being blamed for the origin of HIV, Africans reversed the blame and considered it to be a sabotage against the third world populations (see, e.g., Chirimuuta and Chirimuuta 1989, Panos 1989, Sabatier 1988).

So distinct became the ideological phenomenon of AIDS from the actual disease, that Brazilian writer and PWA Herbert Daniel wrote "aids" with regular typeface to refer to the ideological and political phenomenon, "a significant that means far more than the disease referred by the acronym AIDS" (Daniel 1990:11). The same distinction was followed by activist Silvia Ramos, who notes that

aids arrived to Brazil before the first cases of **AIDS**. An epidemic (the third) [of prejudice] starts to circulate in Brazilian society with a large

impact right in the beginning of the early 1980s. The expectations and excitement of the national soul were bigger than the effects caused when the disease arrived, grew among the population and, now, explodes... a few years later. (Ramos 1990:8)

Contrary to the other countries with Latin-rooted languages, where AIDS became SIDA (for Syndrome de l'Immuno-Déficience Acquise, in French, Sindroma de la Imuno-Deficiencia Aquirida, in Spanish, or Síndrome de Imunodeficiência Adquirida, in Portuguese), Brazil created its own vocalization of the international English-based term "AIDS" [A-ii-d-e-sh] to refer to the epidemic. In the first series of manuals edited by the government, setting guidelines to treat and prevent the epidemic, it was referred as SIDA/AIDS (Ministério da Saúde 1987, 1988a, 1988b); in clinical settings the disease was and often is referred to as SIDA, as in other Portuguese-speaking countries. Publicly, however, the disease came to be known as **AIDS**; government, activists, media and health professionals alike transformed what was originally an English acronym into a noun. This fact is not unrelated to its repeated use by the media.⁶⁹

⁶⁹Brazilians sometimes argue that "sida" would be easily mixed with "Cida", short for Aparecida or Alcida; in their view, the choice of a personal name for a disease would stigmatized the women with that name. They did not seem to know that "aids" as an English noun (and verb) pre-existed the epidemic.

In Brazil, like in many other non-U.S. settings, AIDS become news for the simple fact of being from the United States (see Ramos 1990:9-10). Just as a hurricane in Miami was more likely to make news than one in the Philippines, a lethal epidemic in the developed countries became world news. Moreover as this mysterious disease seemed to affect only gays, another exotic category. The most morbid expectations were raised in the Brazilian media. Was it going to arrive to the country? Was Brazil **that** modern? In a country split in the double identity of developed-while-underdeveloped, it is not uncommon for the media to explore the ambiguities of collective identity. If Brazil were to have AIDS, it meant that at some level it was a developed country; after all, AIDS was a "first world" disease. As a consequence, some of the early cases of AIDS attracted the spotlight, in contrast to the shameful silence given to the endemic diseases that affected and affect the population by the millions; those are not fit to print. Readers do not want to know about the 8 million people with Chagas disease, the 13 million with schistosomiasis, or 460,000 new cases of malaria in 1987 alone (see Cohn 1995:85-86).

AIDS, however, was not the regular shameful trivia; it deserved media attention as a **Doença de Primeiro Mundo** (disease of the first world), popularly referred as **doença**

de rico (disease of the rich).⁷⁰ As Moraes and Carrara (1988a) note, the symbolic opposition between "third world" and "civilized world" was the most complex among a repertory of imageries used by the media to portray the epidemic, and that included gender, sexuality, and death. Coming from the "primitive heart of Africa" to "slash" New York, the "capital of the world," the new epidemic was portrayed in the media as the "revenge of the oppressed"; passing from the monkeys to Africans, from those to Cubans and Haitians, the virus was transmitted to U.S. gays on vacation; from primitiveness to modern decadence, a range of symbolic connotations loaded the account (Moraes and Carrara 1985a:17). The epidemic in Brazil was portrayed in the media as the encounter of both the "civilized" and "primitive" extremes, the authors note.

It gets delirious when the presence of the disease among us is seen as a sign of distinction and civilization. When [the magazine] **Manchete** publishes in the first page the title "AIDS: Brazil is already the vice-champion," it is not just a morbid joke: there is also a certain amount of pride in there. AIDS becomes the proof that among us exists the life-style of the big American metropolises, that we are also "civilized," that the "sexual revolution" happened here also. (Moraes and Carrara 1985a:17)

⁷⁰A similar association is reported for Tanzania, where the Swahili word **hella**, for "money", was used to qualify the new disease that affected rich traders and fishermen (WHO 1994a:3), much in the same way it affected well traveled gay men in Brazil. Those cases happened to be more visible, like the North American cases had been more visible on a world level.

The representation of AIDS as an affliction of the rich remained solid for many years, due to the treatment the media gave the epidemic, which was almost exclusively centered on celebrities with AIDS. We know now that the epidemic probably affected the different social strata evenly since its early years (Granjeiro 1994), but this fact remained unnoticed. The incidence of AIDS among the poor deserved media attention (e.g. **Estado de São Paulo**, May 18 1991) and public awareness only after the question of AIDS and poverty attracted theory and media coverage in the United States. In the year 1991, the words "pauperization" and "Africanization" became media favorites in the description of the epidemic trends in Brazil. WHO's epidemic patterns I and II were at the background of the classifications, and when some women became sick the media interpreted it as a move from pattern I to pattern II, equated to a tendency labeled "Africanization." The topic appeared already in 1987 in the daily **O Globo**, as part of an interview (**O Globo**, November 15, 1987) and was often attributed to the international agencies like WHO (**Folha de São Paulo**, August 8, 1991) or PAHO (**Folha de São Paulo**, October 3, 1991). It would also become a as speculative motive for general confusion, misinformation, and the repetition of stereotypes. This was the case with an article from **O Globo** in April 13, 1989, which combined the presence of HIV-2 in Brazil with the stereotypes on poverty like undernutrition, poor hygiene, and promiscuity, as

the ideal conditions for the explosion of AIDS, through a change in the patterns of transmission: instead of the propagation by risk groups (homosexuals, injecting drug abusers), today dominant all over the world except in Africa, the passage to the heterosexual transmission (O Globo, 4.13.1989)

Giving to the topic a racial connotation that is rarely made explicit, the article further suggested that it was the concern with the Africanization of AIDS in Brazil that had led FIOCRUZ to send its main AIDS researcher to Bahia in order to create a front research laboratory for the surveillance of the epidemic, because

the area, besides having a large number of people of African descent, has the basic conditions for the propagation of the virus in the heterosexual population (Globo, 4.13.1989)

Virtually all the researchers I interviewed dismissed the notion of "Africanization," both on its ideological terms and on biological ones. In fact, the variants of HIV found Brazil belong to the same "clade," or group of variation, as those of United States and Western Europe, which are HIV-1-B. Also, the dominant mode of transmission is sexual and from men to men, followed by men to women, and with fewer, but existing, cases of women to men

transmission.⁷¹

The association of AIDS with privilege in the beginning of the epidemic in Brazil had two sorts of impact: on the one hand, it was used as an excuse for the government's lack of attention to the disease (see Ramos 1990:13), with the claim that AIDS affected a very small minority (the "first world within") who could afford their own health care abroad, while the government should use its resources for the massive endemic diseases affecting the deprived in massive numbers, like malaria and tuberculosis. In a full page article of the daily **Globo**, in September, 8, 1985, Health Minister Carlos Santana declared that even

⁷¹The female-to-male HIV transmission raised intense debates. Based on a small universe of research, physicians from the Gaffrée e Guinle AIDS unit sustained publicly that there was no evidence of women-to-men transmission. Even though the claim was dismissed by a number of local doctors and activists, as well as by the literature, it remained as an ideological contribution to the already strong resistance regarding the practice of safer sex. This translated in men, oblivious of their own serostatus, avoiding condoms when having sex with women, to the later's blatant disadvantage in a context where gender empowerment is unbalanced to begin with. As a pragmatic choice, most prevention campaigns have focused on the use of condoms as the only way to avoid HIV infection. Easier to manage than issues like power, negotiation, gender, and alike, the focus on condoms had its own problems, particularly giving their extraordinary price: in 1991, one unit costed more than the equivalent to one U.S. dollar, while the minimum monthly wage was below U.S.\$100.

though his office was taking a series of measures against AIDS, this disease could not really be considered a priority. There had been only 415 confirmed cases of AIDS, when Chagas disease alone had 4.5 million, schistosomiasis had seven million, malaria had 385,000, leprosy had 206,000, and the Ministry of Health was treating 88,000 cases of tuberculosis, not to mention the 1,5 million cases of sexually transmitted diseases like syphilis and blenorrhagia. On the other hand, the publicity brought by celebrities to AIDS helped mobilize solidarity campaigns and fund raising. After some pop stars and TV idols got sick or died,⁷² support from the performing arts community for the AIDS cause in Brazil increased significantly.

The first publicized case of AIDS in Brazil reinforced its stereotype of a disease of the rich and famous; it

⁷²Two contrasting examples from the year 1989 are those of rock singer Cazuza and TV-Globo actor Lauro Corona. The young and handsome Corona hid his condition and kept acting in a soap opera until he could no longer stand; he died in denial, appalling a multitude of fans and friends. In his memory, other actors and actresses campaigned against the prejudice that surrounds AIDS, so that no one else had to endure the same type of solitude. At about the same time, and yet counting on a different personality and social support (his own family ranked higher in Globo itself) Cazuza came out as a PWA; his disclosure was used as a tool against the disease, which he fought with all possible strategies. He became the local AIDS-poster-boy, lend his face to front pages of mainstream magazines and to serve as a role model for disclosure and fight. His mother Lúcia Araújo got involved in anti-AIDS activism and created a foundation after his death, in 1991, **Sociedade Viva Cazuza**, that provides support and health care to children with AIDS.

happened with São Paulo's gay designer Markito in 1983. He was seen as a cosmopolitan gay traveler who got AIDS in New York. He was also portrayed as the irresponsible type who went back to the metropolis for fun and party instead of getting treatment (*Isto É* 6.15.85, quoted by Moraes and Carrara 1985b:25).

Cosmopolitanism contributed at least as much as homosexuality for the initial symbolic imprint of the new epidemic, and Markito's case was used as evidence that Brazil shared the international jet-set phenomena perceived as AIDS. Contrary to the homophobic censorship that in the United States prevented the publication of early notices on AIDS, in Brazil a show was made of this disease. While in the United States the rampant number of cases could hardly get any coverage, in Brazil the few initial cases had to struggle with excessive morbid attention.⁷³

A second basis for public awareness, and one that mobilized a more political type of attention and action, came with another of the early publicized cases: that of

⁷³Media's morbid attitude included an eager search for the "aidético" (the medical name given to AIDS patients, later doomed as politically incorrect by the PWA organizations) even in hospital settings. Once a doctor commented on how she had disappointed a journalist just by referring that she handled AIDS as if it were any other disease. While the health professionals tried to build a pattern of normality in the treatment of AIDS, the media insisted on its "abnormality". The magazine ended up not publishing the story of "normality" in the professional care of AIDS. For a lengthy analysis of AIDS treatment in Brazilian media, see Galvão 1992a).

Henfil, the well-known and beloved political cartoonist who had criticized and fought the military dictatorship with his art. Henfil was an hemophiliac iatrogenically contaminated with HIV through hemotherapy, as were his brothers Chico Mário, a musician, and Betinho, a politically engaged sociologist widely known as a community organizer.⁷⁴ **Betinho** (Herbert de Souza) helped shape a politicized perception of the epidemic as a public issue that involved empowerment, citizenship, social compromise, disclosure of government policies, social control, and the fight for basic rights. The issues of illegal blood banks, corruption and government inefficiency were made visible through the commentary on Henfil's disease and painful death, and helped mobilize wider agendas.

The fight for citizenship in a country that was emerging from an authoritarian military rule (1964-1985) provided a larger and better umbrella for anti-AIDS social

⁷⁴ Betinho (Herbert de Souza) heads the large umbrella-NGO IBASE, the Brazilian Institute for Social and Economic Research, which hosts a number of applied social research projects. IBASE pioneered the management of updated and large-scale documentation, electronic networking and international conferencing, public intervention on social causes and critical dialogue with the governments about specific issues. Betinho is often consulted by progressive ministers and presidents. A charismatic figure, in 1994 he led the campaign of "citizens against famine", which almost brought him the nomination for the Nobel Prize on Peace (the candidacy was jeopardized by his past acceptance of illegal gambling money as emergency funds for the AIDS organization ABIA at one of the times it was at the verge of bankruptcy).

organizing than a gay-based movement might have provided, many activists argued.⁷⁵ There was no distinct and established gay community⁷⁶ in Brazilian cities as there were in New York and San Francisco. Moreover, there is a pervasive ideology that denies the existence of homophobia in Brazil, similar to the denial of racism -- which, naturally, takes other and more insidious forms (see Bastide and Fernandes 1951, Burdick 1995, Fernandes 1979,

⁷⁵The interviews and exchanges on which this statement is based were collected in the years 1989-1992, and mostly in Rio de Janeiro. People who had participated years before in the extinct gay groups like **SomoS**, or people who were gay but had never participated in any gay group, argued that the participation in a larger platform, including hemophiliacs, blood recipients, and women under the banner of citizenship, was a better strategy for fighting AIDS and spreading prevention messages. Some members of the existing gay groups, like Grupo Gay da Bahia and Atobá, preferred to include AIDS in their many activities as gay-identified groups. G.G.B. remained very critical of what became the mainstream in AIDS activism, particularly the large agency **ABIA**, from Rio.

⁷⁶For many of my "informants" the notion sounded alien and very (north) "American". In their analysis of the early media responses to the new epidemic, Moraes and Carrara (1985b) criticize the rapid adoption by the media of the term "gay community". The authors considered the literal translation of the term as culturally inadequate in the Brazilian context at the time. However, with the implementation of the fight against AIDS and the strengthening of community-based organizations, the term **comunidade homosexual** (gay community) became more frequently adopted. In 1995, Rio de Janeiro hosted the annual International Lesbian and Gay Association (ILGA) meetings, an event in which federal and state government officers praised the importance of the involvement of the gay community in the fight against AIDS.

Fry 1982, 1989, Skidmore 1992, Sheriff 1995, Twine 1995).⁷⁷ If there is no homophobia, the argument goes, there is no sense for a gay movement or gay-based actions.

The situation is more complex than that. Scholars have portrayed the subtleties of Brazilian sexual culture in a number of diverse ways, from a "closeted" gay life under a repressive homophobic culture (Mott 1995) where original categories like that of **entendidos** develops (Guimarães 1977, Whiten 1979), incipient gay movements struggle (MacRae 1990), bringing a shift from hierarchical to egalitarian relations (Fry 1982), to a **sui generis** sexual culture where the categories of "gay" and "straight" are subverted by floating erotic meanings, like **sacanagem**, structured around transgression (Parker 1987, 1991a, 1992, and also Fry and MacRae 1985, Perlongher 1987); there are also detailed ethnographic descriptions of clandestine urban gay life (Guimarães 1977, Terto 1988), historical interpretations of same-sex interactions in past centuries (Mott 1985, 1988a, 1988b) and cultural interpretations of sexual meanings (Fry 1982, Parker 1991a).

⁷⁷Deserving a separate analytical treatment that is not in the scope of this work, the pervasive form of local racism is nevertheless relevant in several ways. Not only does it provide a paradigm to better understand the local sexual ways but it also has a subtle impact on topics that appear without reference to race, and where it is yet present, like the "pauperization" of the epidemic, or the "Africanization" of Brazilian AIDS.

Regardless of the interpretations, the fact is that the rising gay movement that developed in the late seventies as part of the several social movements of the **Abertura** (literally, "Opening," the movement of democratization within the military dictatorship that characterized the late 1970s), like **SomoS** and **Lampião**, did not last long (see McRae 1990). At the beginning of the epidemic in Brazil only a few of those groups remained. Even though they addressed the problem and developed AIDS-related work, like **Atobá** in Rio de Janeiro and the **Grupo Gay da Bahia** (GGB) in the city of Salvador, state of Bahia, these groups did not provide the leadership in the fight against AIDS. It was not under gay denomination that the bulk of organized responses to AIDS were developed; rather, it was under the banner of human rights, and with the particular format of NGO (non-governmental organizations).

ONG, for **Organização Não-Governamental**, which literally translates as NGO, Non-Governmental Organization, became the most popular acronym for the community-based organizations involved in the fight against AIDS in Brazil. Rather than supported by local gay organizations, Brazilian AIDS activism was largely connected to the international mobilization against the epidemic. The crystallization of

the organizational form **ONG**, NGO, symptomizes at some level its international support and external aid; the link between this acronym and WHO-sponsored forums would only increase in the following years and expand to other fields.⁷⁸

As other community organizations throughout the world (Altman 1995, Arno 1989, Nelkin et al. 1991, Pollak 1994, Van Vugt 1994, Watney 1994, Wolfe 1994), NGOs were central players in the social movement responding to AIDS in Brazil in the decade 1985-1995. In this chapter I will discuss their role in the production of knowledge on the epidemic, examine their morphology and dynamics, their networking efforts, and their relationship with other intervening social actors such as international agencies, the Brazilian government, and the medical establishment. Unlike the community organizations examined in the United States, Brazilian NGOs are defined not only in relationship to other local social forces, like the government or the medical establishment, or structured by the local dynamics of people with AIDS, but their existence is deeply intertwined with external and international social forces, both through funding and through the sharing of knowledge.

⁷⁸ The environmental Earth Summit in Rio 1992 and the Conference on Women in Beijing 1995, for example, would both have their separate NGO forums.

The year of 1985 may be described as the first moment of international awareness on AIDS (see chapter 3). It was the year of the First International Conference on AIDS, and of the launching of WHO special programme. It was also the year of Rock Hudson's death and its scrutiny by the media. Public awareness also started at that time in Brazil.

Cadernos ISER, the journal of the large organization ISER,⁷⁹ dedicated its seventeenth issue to AIDS and counted with the contribution of several scholars and political activists (ISER 1985). A group of São Paulo's citizens, including health professionals and social activists with or without experience in the gay movements within **Abertura**, created the first and forever largest **GAPA, Grupo de Apoio à Prevenção à AIDS** (AIDS Prevention Action Group). The following year gave birth to the largest Brazilian AIDS agency, the **Associação Brasileira Interdisciplinar de AIDS** (Brazilian Interdisciplinary AIDS Association), or **ABIA**, in Rio de Janeiro. ABIA's founders included medical and social scientists, physicians, social activists and a number of citizens concerned with the Brazilian government's little response to the epidemic.

⁷⁹The **Instituto Superior de Estudos de Religião**, Institute for the Study of Religion, is another umbrella NGO whose scope goes much beyond its title and promotes different social intervention programs as well as research. It is basically funded by religiously inspired donor agencies from Northern European countries like Holland, Sweden, and the U.K.

During the following decade, a number of similar but smaller organizations multiplied throughout the country, associating this particular organizational form to the social response to AIDS. In 1989 there were 51 AIDS-NGOs, counting both the ones that added AIDS to their concerns and those who were created specifically to fight AIDS (Rede Brasileira 1989a:4); one year later there were 60 (Valinotto 1990:6-7), and 87 were reported in 1992 (Solano 1992:8); finally, the 1994 catalogue published by the government counted 140 (Ministério da Saúde 1994a:91). Retrospectively, 22 organizations claimed to be working with AIDS as early as 1986; eleven had initiated their work in 1987, eight in 1988, and the number increased the following years. Twenty organizations started with AIDS work in 1989, eighteen in the following year, and again eighteen in 1991; in 1992, twenty five initiated activities, and seventeen were counted in 1993 (Ministério da Saúde 1994a:92).

"ONG" was an uncommon term that gained popularity in the 1980s (see Landim 1988:24) until near exhaustion by the 1990s in several fields of social intervention in Brazil, in Latin America (see Reily 1995), and worldwide. Regarded as an "imported" term, "coined in the Northern countries" (Landim 1988:25), "adopted for convenience" (Fernandes 1988:8) from the jargon of international aid agencies, and consolidated during the time of **Abertura**, the term became

irreplaceable in the Brazilian repertory of social institutions. Its "myth of origin" refers to the 1950s and to religious activism (Fernandes 1988:9; see also Fernandes and Carneiro 1995:72). Indeed, the Catholic grass-roots movement which had its most visible expression in **CEBs** (base ecclesiastic communities) provided an important background experience for many of the NGOs that bloomed later, including those with AIDS support services. Left-wing politics were another source of organizing (Fernandes 1988:9; Fernandes and Carneiro 1995); it was in the late 1960s, when the dictatorship was particularly harsh, that this organizational format matured, often as the possible legal face for political action (see Landim 1988:31). A third source for the NGOs derives from universities. Non-profit agencies act like magnets for "organic intellectuals": they are appealing work sites for those who want to avoid the sterility of ivory towers, the slow bureaucracy of public service, or the stress and materialism of corporate business; in NGOs, university graduates can fulfill their social commitment agendas by providing "intellectual support for the popular movements" (Fernandes and Carneiro 1995:75), whether they do it full or part-time, out of strong political faith or just as a job in the market.

The social response to AIDS in Brazil coincided with the period of expansion and consolidation for NGOs. In the

late 1980s, the acronym **ONG** occupied the symbolic spot where there had been **movimentos** (movements), **associações** (associations), and **grupos** (groups), for the field of AIDS as well as for other spheres of social intervention. Also, the term **ativista**, tailored after the international icon "AIDS activist," replaced the older term **militante**, seasoned in the local political left-wing. A new social vocabulary had emerged in response to AIDS.

AIDS-NGOs, like NGOs in general, varied greatly in form and function. They might resemble business offices housed in mansions with several full-time employees, high-tech equipment, a number of on-going projects, multiple international connections, and renewable generous grants; or they operated out of someone's back room, gathered volunteers, and lived off raffles, button sales, small donations and volunteer work. They could be committed to political intervention or devoted to assistance work. They could act as monitors or critical partners of the government, or merely take a day-by-day perception of their area of action. They implemented research projects, organized conferences, and published competitive pieces of work; or they engaged directly in social intervention without ideological, political or scientific guidance. Such diversity is sociologically recurrent: "If heterogeneity is the rule within and among Latin American countries, it is gospel among NGOs and social movements" (Reily 1995:22).

In the social profile of Brazilian AIDS NGOs in 1992 drawn by Nelson Solano from GAPPA-São Paulo, they are presented as a diverse group that shares common goals. His survey included 87 organizations, of which 51 were considered autonomous; 19 had religious affiliations, and 11 were linked to sexual emancipation groups. They were seen as a new and spontaneous social phenomenon which the analyst considered mostly autonomous, except for the religious-affiliated groups (Solano 1992:9). The author's formalist reading fails to account for the driving force of funding that helped create, sustain, and sometimes define the work of these organizations; as NGO analysts Ruben César Fernandes and Leilah Landim had commented, NGOs do not like to refer to their sources of funding and take it quite matter-of-factly (see Landim 1988:47-48).

Solano contrasts AIDS-NGOs to previous Brazilian social movements, who pretended to represent the "popular classes"; the new movement did not have that pretension, nor did it necessarily oppose the government, but rather its health policies. The AIDS-NGOs seemed related to the urban centers with a relevant epidemiology or the presence of clearly defined homosexual or religious communities, which are implicitly acknowledged as the other driving force for this social movement. The author blames amateurism, absence of reflection, and excess of pragmatism, with the corresponding absence of political,

educational, and social goals, as well as an absence of articulations with other sectors of society, for the identity crisis and difficulties experienced by the movement (see Solano 1992:9-10).

Several attempts to organize and articulate the Brazilian AIDS-NGOs under a common structure took place, often inspired or supported by international networks. Among the many GAPAs that were created in the meantime in the different Brazilian cities, to a total of 18 in 1992 (Galvão 1992b:7), there were a few channels of communication and cooperation, such as the exchange and borrowing of materials, ideas, styles, and the sharing of experiences. Between 1987 and 1989 alone there were five nation-wide inter-GAPAs meetings (Solano 1992:12).

Even though much of the constituency of AIDS-NGOs was gay, it did not follow a pattern of gay-based AIDS-activism from the Northern hemisphere; rather, it went together with the global efforts promoted by international funding agencies. The AIDS-NGOs movements in Brazil had experienced a turning point with the official acknowledgement of their role in the global fight against AIDS by the World Health Assembly in May 1989 (WHO 1989c). This acknowledgement followed the attempts of the Global Programme on AIDS to formally include the Community Based Organizations in the fight against the epidemic (WHO 1989c). This move helped empower, strengthen and fund local groups throughout the entire world.

The highest moment of exaltation in this collective movement was probably the Forum "Opportunities for Solidarity," sponsored by the World Health Organization in June 1989 in Montreal, prior to the Fifth International Conference on AIDS. Coming from everywhere, more than three hundred organizations and six hundred activists participated and exulted with the acknowledgement of their transformative power. Some were already incorporated into the inner planning and executive core; ABIA, from Brazil, participated in the organization of the meeting (ABIA 1989b:12).

The language of networking was a key in the Montreal meetings. **ICASO, the International Council of AIDS Service Organizations,** and the future **Latin American Network of Solidarity** were given as examples of integrating structures for local action. The forum "inspired the Brazilian NGOs who participated to seek regional and global forms of participation and response" (Galvão 1992b:10). Such forms were to be found, at least partially, by means of "the articulation through national networks, as a first step to the formation of regional and international networks, interconnected through ICASO" (Galvão 1992b:10).

NGOs lived then and there intense moments of empowerment and stood out among the other social actors involved in fighting AIDS, such as medicine, science, and the public administration. Several Brazilian organizations

were present in Montreal: from Rio de Janeiro alone, there were **ABIA**, **GAPA-RJ**, the gay group **Atobá, Prostituição e Direitos Civis** (Prostitution and Civil Rights), and **ARCA** (Ação Religiosa Contra a AIDS), these last two linked to **ISER** (the High Institute for the Study of Religion, a large umbrella-NGO with many different social research and intervention programs); the **GAPAs** of São Paulo and Bahia, **GETAIDS**, from Brasília, and the Pernambucan gay group **Movimento Antônio Peixoto** (Rede Brasileira 1989a:3). They returned home with the enthusiasm to create a national network and execute common projects.

Shortly after, the first meetings of the AIDS/NGOs Brazilian Network of Solidarity were held in Belo Horizonte, Minas Gerais (June 14-16), gathering fourteen organizations: the **GAPAs** from São Paulo, Rio de Janeiro, Bahia, Belo Horizonte, Pernambuco, Rio Grande do Sul, Santa Catarina; **ABIA**, **ARCA/ISER**, **Prostituição e Direitos Civis/ISER**; the recently formed group **Pela VIDDA** (an association of people living with AIDS, their families and friends, inspired by Herbert Daniel); the Group **Solidariedade**, from Belo Horizonte; the **Lambda** support center, from São Paulo: and the young national "names"/quilt project, **Projeto Nomes**.

A committee named at those meetings, including Nelson Solano (GAPA-SP), Jane Galvão (ARCA/ISER), Ranulfo Cardoso (ABIA), and J. Eduardo Gonçalves (GAPA-RS), was given the

role of expanding the network and raising funds for the next meetings. Their survey counted 51 NGOs and obtained international funds from the British agencies CAFOD (Catholic Fund for Overseas Development) and the Save the Children Fund; from the US-based Ford Foundation, and national donations from a local industry and a private donor (Rede... 1989a:5). Thirty-eight NGOs participated at the meetings held in Porte Alegre. There were already thirteen **GAPAs**: adding to those present in the previous meetings there were also the GAPAs of Baixada Santista, Ribeirão Preto, São José dos Campos and Taubaté (all in the state of São Paulo), plus Belém (Pará) and Fortaleza (Ceará); there were groups with similar names, like **GEAPA**, **GETAIDS**, and **GEPASO**; there were now three **Pela Vidda** groups (Rio de Janeiro, São Paulo, and Rio Grande do Sul); four delegations of the **Nomes** project (the national coordination, and the delegations from Florianópolis, Salvador, and Santos); there was **ARCA/ISER** and **ABIA**, from Rio, and the smaller **ALIA**, from Londrina, Paraná; there were several gay-denomination groups (**Atobá** and **Turma OK** from Rio, and the **Grupo Gay da Bahia**); volunteer and support groups such as those linked to the **Hospital Emílio Ribas** (SP), **Solidariedade** (MG), **Solidariedade** (SP), **Esperança**, **PRAIDS**, **MAPA**.

The enthusiasm of the participants reached its highest moment with the reading of the letter of support to the

Brazilian Network personally signed by the director of WHO's Global Programme on AIDS, Jonathan Mann (1990). The proposal for a chart of principles for the network was presented and discussed (ABIA 1989d, Rede...1989b), as well as the declaration of rights of the person living with AIDS, which the **Pela VIDDA** group had developed as their centerpiece (Rede... 1989c); a document with the statement of principles for the network was approved (Rede... 1990).

There was a third series of meetings in April 1990 in Santos, where some "traumatic" (Galvão 1992b:11) moments brought unsurmountable differences to the surface. A major conflict split the participating organizations and "postponed the dream of the creation of a Brazilian Network of AIDS-NGOs that included everyone, from Oiapoque to Chuí" (Galvão 1992b:11).

Social commentators relate the schism to the contradiction between, on the one hand, the organizations whose constituencies pre-existed the AIDS crisis (like gay or prostitute groups) which, having suffered repression under the previous regime, were now willing to work with policy makers towards AIDS prevention;⁸⁰ and, on the other

⁸⁰Often, government officers commented that it was easier to work with this type of groups with the self-assigned AIDS/NGOs. I could observe that the groups Atobá in Rio or GGB in Bahia, both of gay affiliation, were more willing to work with the board of health or the medical institutions than, for instance, ABIA, whose critical stance often prevented them from cooperating with government- or medical-sponsored pragmatical programs. Prostitute groups, also, cooperated with the government for joint programs, like the ISER affiliated group

hand, AIDS-NGOs who integrated anti-dictatorship activists and would not consider negotiating with authorities that continued the structures of the authoritarian regime which they had fought and did not trust (Valinotto 1990, 1991; Parker 1994a:40). There were a number of other issues at stake, such as class, regional tensions, and the ever underlying race and gender tensions. But, no matter how critical they might have become, they were not what counted the most at that moment.

My argument, from the analysis of the worldwide processes, is that the critical reason for the breakdown of the movement did not rely as much on its internal characteristics, but rather on its background international context. In spite of its inconsistency, looseness and contradictory nature, the movement might have continued if there had been funding, leadership and support for it. However, the period of revolutionary transformations was over, and there was not a full perception of that fact at a local level, at least for the majority of social actors involved. Institutional attempts to create organized international networks like ICASO (International Council of AIDS Service Organizations) and the Latin American Network

"Prostituição e Direitos Civis" (prostitution and civil rights), that produced a number of leaflets (e.g. ISER 1990) under the program "Previna" (see Braiterman 1991a, 1991b).

of AIDS/NGOs equally failed, an issue that Brazilian analysts attributed to conflicts regarding representation of groups and countries, allocation of resources, power competition, and bureaucratic obstacles (Solano 1992:19).

The problems were of a wider scope, though. A larger shortage of funding and support was taking place everywhere and anywhere. In New York city, CRIs were about to lose funding. The Global Programme on AIDS had changed leadership, and the world seemed shifting into another direction. It might be that the "utopic moment" of transformative action was over, ceding pace to more institutional, bureaucratic and medicalized approaches.

Yet, the epidemic progressed with growing evidence that technical responses were not sufficient to stop its spread; and the more the social intervention was needed, the less it was proportionally supported. Already in 1990, the expectations for the Sixth International Conference on AIDS (San Francisco) had turned into frustration. NGOs boycotted the conference due to the U.S. restrictions on the entry of HIV-positive travelers, which prevented people with AIDS from participating and from giving their irreplaceable contribution to the global efforts (see AHRTAG 1990a). It contradicted the entire rhetoric of WHO and AIDS action. The boycott of the San Francisco conference was closely followed and respected by Brazilian NGOs (ABIA 1990a, ABIA 1990b).

The second international meetings of AIDS-NGOs, held in Paris in November of that year (AHRTAG 1990b:1,11), did not raise new strength for the movement either. Instead, for many activists those meetings marked the end of a dream of equality and ability to transform the order of things. According to a delegate from São Paulo, the differences that in Montreal had been seen as the ferment for the multiplication of exchanges had now transformed into insurmountable barriers (Bouchara 1991:9). One of the things that shocked Brazilian activists the most was the type of exclusionary identity politics adopted in the fight against AIDS. Two of the delegates from Brazil to the Paris meetings, untested for HIV antibodies by their own choice, were not allowed to a meeting supposed to be exclusively for HIV-positive people. At the time, Brazilian groups fought hard for inclusive politics, using the line that "we all live with AIDS," a motto of the Pela VIDDA group.

The short one and a half years between the NGO meetings in Montreal (June 1989) and in Paris (November 1990) were the peak of exacerbation for this social movement. There was a shared belief that something completely new was going on. Jonathan Mann had referred to it as a Health Revolution: for the first time, the affected

communities were heard, fought for their rights, and challenged their own governments about health policies. People with AIDS had taken into their own hands the responsibilities of organizing, demanding, showing directions for research and assessing the needs for treatments; they turned upside down some of the old assumptions of the medical practice, where patients were voiceless bodies in which symptoms were inscribed to be read and acted upon the sole mighty power of medical doctors. Now, "patients" were (impatient) persons who had voice, awareness, knowledge, and ability to act.

The changes brought by AIDS could have transformed the entire field of health in the world; there was now an officially endorsed and globally disseminated awareness that in order to address some medical problems one had to address questions of poverty, social development, and human rights. The flame faded quickly, though; as in so many other social upheavals, the goal of equity was undermined by the inequities of real life, and the differences within the social movement crystallized into antagonisms and inability to cooperate. International funding ceased to promote vaguely defined social goals that could be locally interpreted at will, and instead directed quite closely the projects chosen to be funded. After 1991, the belief in radical transformation gave place to more limited ambitions, short-term goals, and to more pragmatic as well as more fundable proposals.

Internationally and locally, AIDS had become more "domesticated" towards the side of the medical establishment; there were more drugs and therapeutical approaches, less fear and panic, and more experience on the part of the health professionals and the pharmaceutical industry. The radical activist energy was drained by losses, burn-out, and less international funding. Pragmatic alliances appeared as a possibility: with the government, with the medical sector, with the scientists or the local corporations. After 1992, the institutionalization of a new National AIDS Program in Brazil with a number of social interfaces, and a significant amount of funding from the World Bank, helped redefining much of the landscape for local activism.

From the activists' perspective, a strategy which defined a successful platform for expanded cooperation started in 1991 with the People Living With AIDS Meetings held by the **Pela VIDDA** group, Rio de Janeiro. Pela VIDDA had been created one year earlier due to the impulse of Herbert Daniel, a Brazilian PWA and writer who had perhaps the strongest single-handed influence in the local movement of response to AIDS. Daniel had been a radical revolutionary with periods of exile in Europe. On his return to Brazil at the time of **Abertura** he had integrated a political campaign as a gay candidate in a small ecological party. A brilliant speaker and inspired writer,

Daniel could cheer an audience as well as persuade a funding agency. His influence touched mainstream international agencies, and the Global Coalition's **AIDS in the World** (Mann et al. 1992) is dedicated to his memory. His fight against the inevitability of death by declaring a commitment to life and solidarity as a Person with AIDS made him a role model for younger PWAs and brought much energy into the Brazilian NGOs as well as to international AIDS settings. One of Daniel's biggest legacies was the creation of the **Pela VIDDA** group in 1990, while he was a staff member and on the board of ABIA. "Pela VIDDA" simultaneously means "for life" and is an acronym of "for the Valorization, Integrity, and Dignity of AIDS Patient."⁸¹ The group's headquarters were literally in ABIA's backyard; then, ABIA's headquarters were a mansion in Jardim Botânico, and there was space enough to accommodate the "offspring" organization with which a symbiotic connection was kept alive for years.

The PWA meetings format responded to pragmatic needs and helped organizing further actions and projects. A number of factors may have contributed to the success of the new effort: organizations had matured in the meantime and benefited from earlier experiences; the epidemic had

⁸¹With the increasing use of **Pessoa vivendo com AIDS** (PWA) the early adoption of **Doente de AIDS** (AIDS patient) was abandoned.

expanded and gained visibility; other social forces were more prepared to articulate and interact with NGOs; people with AIDS, rather than self-assigned experts, took the responsibility of defining the priorities and directions for action.

The formula of the **Pela VIDDA** meetings remained consistent throughout the following years in creating a national space for discussing the social issues of the epidemic in Brazil, and provided a platform for collective debate on the most important questions -- how to live with AIDS, how to implement education and prevention, how to negotiate health policies with the federal and local governments, how to handle the loans from the World Bank and the WHO- or NIH-sponsored projects for local participation in HIV vaccine development.

Simultaneously, in August 1991, **GAPA** São Paulo coordinated a successful inter-NGOs meeting, gathering over 70 organizations (see Parker 1994a:42). Rather than repeat the failed attempts to institutionalize consensus, the aim of the meetings was limited to the discussion of specific issues like vaccine trials, and to help organizing action for the purpose.

This type of forum gathered more interest and success than the previous ones. From then on, **Pela VIDDA-RJ** organized yearly the "National Meetings of People Living With AIDS," which gathered delegates from the entire

country, plus scholars involved with AIDS research (microbiologists, clinicians, social scientists, or epidemiologists), as well as international activists, government, WHO officers or delegates from the Global AIDS Policies Coalition.

As a whole, the social response to AIDS in Brazil was largely articulated to the international movement; the synchrony between global sponsorship and the expansion/contraction of local activism is documented above in this chapter. The international synchronization, however, was not felt evenly in Brazil. Its reverse side was internal differentiation. Rather than leveling, external aid induces a differentiating process among the local social forces. Some NGOs are, or become in the process, more cosmopolitan than others; while the former hold to international links, the latter are either their subsidiary or struggle in isolation, backwardness, and limited action. In the field of AIDS in Brazil, as the international flows were fast, intense, vital in access to information, and involving large amounts of funding, the differentiation process among locals was enhanced. Cosmopolitan NGOs could better benefit from the international activism energy, know-how, expertise,

educational materials, vocabulary, graphic styles, and funding; those which were able to participate in international forums thereby improved their own networks, expanded their knowledge, visibility, ability to develop projects, to maintain funding and to remain active; with more funding they could recruit more qualified and high paid staff and reproduce their economic status quo through grant writing and international networking.

Some local organizations excelled at being cosmopolitan: **ABIA**, from Rio, maintained a constant exchange with major international NGOs, with the WHO Global Programme on AIDS, with USAID's agency AIDSCOM (later merged with AIDSTECH, forming AIDSCAP), and with major foundations like Ford and McArthur. ABIA was central in ICASO and in the Latin American Network of AIDS/NGOs, had a partnership with AHRTAG (Appropriate Health Resources and Technologies Action Group) in the publication of **Ação Anti-AIDS**, the Brazilian version of **AIDS Action**, and was represented at a higher level in the Global AIDS Policies Coalition. Frequently accused of elitism by other Brazilian NGOs (and dramatically so in the 1991 meetings in Santos), ABIA would not adopt a populist attitude nor lower its standards. Instead, it kept prioritizing research and reflection at a competitive international level, combining it with the task of sharing their expert knowledge, mostly through the publication of a nation-wide newsletter,

Boletim Abia, which documents most of the AIDS social movement, plus a number of target-group publications, videos, media appearances, and conferences.

ABIA's unique style resulted from a rare combination of circumstances. Its first major funding, by the Ford Foundation, launched an early international career from 1986 on. That funding supported an academic-style type of research on the "Social Impact of AIDS in Brazil," which brought together anthropologists Carmen Dora Guimarães and Jane Galvão and the activist/writer Herbert Daniel. Their work (Guimarães et al. 1988) produced a critical examination of the narrowness and cultural inadequacy of the epidemiological models used by the government and local health authorities to define the terms of AIDS reporting.

The explicit purpose of the new agency was to "develop a multidisciplinary approach to the issues raised by AIDS" (ABIA 1988a), and attempt "to set forth adequate prevention, education and information policies to face the overall impact of AIDS" (ABIA 1988a). It was part of ABIA's early doctrine that AIDS was a major health challenge with a severe social impact, in the need of a multidisciplinary, engaged response. It became apparent from ABIA's statement that, in the context of AIDS, epidemiological knowledge could not exist separated from social action and intervention:

only global prevention action will be able to check the progress of this virus against which no cure or

vaccine is yet available. Such an action, however, will only be effective if it manages to avoid the harm caused by fear and prejudice for which only solidarity can provide treatment methods.

The AIDS virus knows no boundaries, nor country of class or social group. The ways by which it is transmitted, through sex and blood, involve complex social practices often surrounded by taboos. This turns the epidemic into both a severe medical and epidemiological threat and a huge historical challenge, raising cultural, political, economic, ethical and legal issues.

There are many facets of social life in every country which are brought to bear on the epidemiological profile of the disease. To know precisely what are the multiple aspects is the fundamental topic of prevention activities. (ABIA 1988a)

For that purpose ABIA gathered members from all areas of knowledge --medical and social scientists, media and education professionals, lawyers, politicians, artists, church and community representatives. The NGO stated goals were, in the first place, "to follow and assess AIDS-related government policies and initiatives in Brazil"; as it was made clear, due to the historic public neglect of public health in Brazil, "only through permanent surveillance and joint pressure" would society be able "to claim its right to health, forcing the state to take on responsibility in this area." The second set of goals, "to produce and disseminate updated, accurate and reliable information on HIV-infection prevention and control," was to be achieved mostly through work on **information** and **knowledge**: critique on available information, avoidance of "misinformation," fight against partial and incomplete

information, namely what might produce panic and prejudice; create the means to have direct access to updated data on the epidemic in Brazil and throughout the world; "prepare written and audiovisual aids holding clear and reliable information" directed at various audiences, reached by joint work of ABIA and other agencies; to research on the local social impact of the epidemic in order to "establish the epidemiological, social and cultural profile of AIDS" in Brazil; and to provide consultancy and advisory services to the media and any public demand on the epidemic (see ABIA 1988a).

Counting on the executive skills of Silvia Ramos and Walter Almeida, with the sociologist and nationally known PWA Herbert de Souza (**Betinho**) as president, and having the collaboration of many prestigious founders, volunteer associates and full-time coordinators, ABIA's staff developed early on a number of international connections that enabled the organization to grow and hold a leading role within the international networks of AIDS. What seemed to the smaller NGOs as lavish expenses in airplane travels, computer and modern communications equipment, full-time social researchers, and a number of glossy color publications (see GGB, n.d.), was regular business for ABIA, which never planned to be a community-rooted organization but rather a fast-acting agency oriented to work with information, knowledge, and a critical monitoring of the epidemic.

This orientation characterizes ABIA's first period, lasting roughly from 1987 to 1991. It was focused on a broad intervention in the sector of information coupled with the production of original texts of analysis and reflection, mostly by political writers Herbert Daniel and Silvia Ramos, and combined with international networking, mostly conducted by international broker Walter Almeida.

Throughout the time, internal changes in ABIA led to variations within this orientation. A second moment in the life of ABIA (1992-1994) was characterized by the formalization of multiple partnerships and social intervention in different fields, like work places (ABIA 1991d, Solano 1993), low-income communities (Fernandes 1994), and schools (Monteiro et al. 1994). Herbert de Souza (Betinho) remained as president, while the former staff was lost either to AIDS, burnout, or incompatibilities; the new direction included Jane Galvão, from ARCA/ISER, João Guerra, from NGO community intervention, and as main coordinator Richard Parker, from the State University of Rio de Janeiro, and also a skilled international fundraiser that brought to the agency a wave of new funds, that in 1994 reached the level of one million U.S. dollars a year. The staff was expanded and included Veriano Terto, Nelson Solano, José Stalin, Christina Valinotto, Simone Monteiro, Jacques Schwarzstein, Cristina Castelo Branco, and others. A new managing team with Cesar Behs and Lys

Portella had helped prevent imminent bankruptcy in 1992, and the move of headquarters from the elitist neighborhood of Jardim Botânico to a downtown office building was both a symbolic and a budget-minded act. The Pela VIDDA group moved with ABIA to the new and more accessible downtown location, where there was also ABIA's open resource center with documentation, videos, and books.

In a third phase, starting in 1994, ABIA's profile changed again. Remaining in the downtown headquarters, the staff was dramatically reduced, and the projects of intervention and partnership with communities and corporations were reduced in size and number. The agency focused again on a more academic style of research, as well as on the organization of seminars and the production of social knowledge on AIDS, with partnerships with the university, particularly with the Social Medicine Institute of the State University of Rio de Janeiro (e.g. Parker and Galvão 1994, Parker, Bastos et al. 1994). One particular project that combined research and intervention became central to ABIA's activities: the project "homossexualidades," targeting gay men, executed in partnership with Pela VIDDA-Rio, and sponsored by AIDSCAP/USAID, the McArthur Foundation, and the Ministry of Health (Terto 1993, ABIA 1994, Quemmel 1994, Parker, Mota and Rodrigues 1994). After many years of conceptual elaboration and public education against the link of

prejudice about AIDS and homosexuality, ABIA was now ready, with the support of international funding agencies and the government itself, to address the population that kept standing out in the statistics of illness and risk.

Only a few other NGOs succeeded in establishing their international networks and developing their local action accordingly -- benefiting from funding or privileged knowledge. A successful example is the joint publication, by Pela VIDDA-SP and GAPA-Bahia, of the **Cadernos Pela VIDDA**, a newsletter on treatment news and a glossary of AIDS-related terms where most articles were translated from international treatment activism newsletters. This publication brought innovation and filled an empty space, spreading and sharing a type of knowledge that had been available only to the few English readers with access to international newsletters or conferences (see Gaspar 1992).

The consistent opposition to governmental policies regarding AIDS (or, in activists words, the lack of them) was a central element in the first period of social organizing against AIDS in Brazil. Earlier in the epidemic, public officials had referred to AIDS as an international and foreign issue with little local relevance, especially when compared to the traditional endemic plagues. Public

dismissal and governmental unwillingness to act upon AIDS, until at least 1986, fueled NGOs criticisms; this partially explains why their early efforts were concentrated on persuading the public that AIDS was locally relevant, that adequate measures should be implemented, and that awareness had to be raised. NGOs' assumed that the government would never meet their requests, nor people's needs in general.

The governmental program on AIDS was legally created in 1985, taking effect in 1986; during the following years the program, headed by Lair Rodrigues,⁸² gathered and published epidemiological data and a few manuals for AIDS care that were sent to the health services (e.g. Ministério da Saúde 1987, 1988a, 1988b), as well as lobbied for international support and scientific attention to AIDS. Working through a loosely organized action program, and within a decadent health system in the aftermath of a long dictatorship, governmental action upon AIDS had severe discontinuities. Public awareness campaigns might have had good intentions but were criticized by most vocal activists

⁸²Lair Guerra de Macedo Rodrigues headed the first National Program on AIDS and STDs (1986-1990), was replaced during Fernando Collor's presidency, and returned when this president replaced corrupt Minister of Health Alceni Guerra by INCOR's surgeon Adib Jatene in 1992. Previously a biomedical sciences professor at the University of Brasília, Lair Macedo is personally connected to international bureaucracies of PAHO and WHO and her vitae includes a period at the CDCs in the United States. As a woman, a Northeasterner and a Baptist, she challenges the usual profile of power (male, Southeasterner, catholic or laïc) with an unusual political savvy.

(for a polemic see ABIA 1988c:2 and Mott 1988c:6). Targets for criticism were the government's choice of communication styles, words, priorities, and the slowness or absence of intervention in critical sectors like blood contamination (see ABIA 1988d, 1988e, 1988h, 1988i, 1988j; Ramos 1988:6; see also Tema/Radis 1988). In spite of the shared goal of intervening and containing the AIDS epidemic in Brazil, the governmental and non-governmental sectors had then a quite difficult interaction; while the government had a narrowed medical perception of the epidemic, NGOs, backed by international organizations and by their own political and social science knowledge, insisted on the wider social dimensions of AIDS and on the need to address them as a central strategy for action.

NGOs developed their own expert knowledge about AIDS in Brazil, often rejecting the knowledge used and disseminated by the government, even what we might think of as "technical knowledge." Figures were challenged as under-representing the epidemic (see ABIA 1988c:2, 1988f, 1989a); from an assertion of a level of 30% under-reporting, ABIA estimated later a level of 50% under-reporting, supposed to be even worse in the state of Rio de Janeiro, where the 800 reported cases in 1989 might correspond to over 2,000 actual cases (ABIA 1989a, Guedes 1989). Epidemiological concepts, including the "risk groups," were challenged as culturally inadequate, discriminatory, prejudiced, and

misleading (see ABIA 1988f, 1989c; see also Guimarães et al. 1988:4-5; Ramos 1989:9; Parker 1989a:10); in this area alone, a vast subfield of research on local sexual cultures, drawing from the constructivist view on the local sexual ways (Fry 1982; Fry and McRae 1985; McRae 1990, Perlongher 1987, 1992; Parker 1987), and developed into an international model by anthropologist Richard Parker (e.g. Parker 1987, 1988, 1989b, 1991a, 1992) inspired the rejection of the narrower medical models upon which the epidemiology of AIDS was based. Media campaigns were rejected as either offensive, ineffective, scarce, or using incorrect imagery (ABIA 1988d; 1988e; 1988j; Ramos 1988:6); publications were criticized as too few or too many. A harsh criticism of the government preceded a more "objective" analysis of the contents of governmental efforts and the possibility of working cooperatively towards containing the epidemic. The knowledge and world views from where activists and public officers stood seemed then to belong to different galaxies.

There were historical reasons for the opposition: governments had been headed since 1964 by military dictators, and NGO personnel had politically matured while fighting them: as for the generic NGO activist, "the state was an obstacle, rather than an actor for cooperation" (Landim 1988:45). Even after military resignation to and the advent of civilian rule in 1985, there was no evidence of a substantial change in the administration.

The 1990 presidential elections brought a promise of change, with labor movement candidate Lula and the anti-corruption candidate Collor. They were won by the latter, who proceeded with frantic reforms in the monetary system and multiple efforts to modernize the international image for Brazil. He did not, however, change much in the health structure except to allow the slow and insidious dismantling of the public health care system, with the diminished role of the state and government in public health. The decline on the population's quality of life was blatantly evident during the time of my fieldwork. Ironically, this president was impeached two and a half years after election on grounds of corruption. His first appointed minister of health, Alceni Guerra, was dismissed earlier for proven corruption when allocating funds of the 1991 anti-cholera campaign for his own electoral benefit and overpayment of "emergency" purchases, often defined by the interests and profit of his political supporters.

During Alceni Guerra's mandate (1990-1991), the little that the government had previously done to fight AIDS was replaced by fewer and constantly postponed actions. AIDS officer Eduardo Côrtes, who at the time of appointment (1990) was better praised than previous officer Lair Rodrigues, promised fast action and an "aggressive" media campaign. The campaign came to light a few months later, funded by a consortium of corporations. Its tagline "**Se**

você não se cuidar, a AIDS vai te pegar" ("if you don't watch out, AIDS is gonna get you"), combined with naked silhouettes of a woman and a man with targets on their genitals, was seen as of bad taste and inefficient. Yet it was bland when compared to the TV-spots of the same campaign. On those, a succession of different people with illnesses like cancer and tuberculosis announced to the cameras that they had been ill but had been cured. In the end, the screen brought in the face of a young man that announced he had AIDS and had no cure. Stating the opposite of what the social movement of PWA dignity had been fighting for, the campaign was declared altogether a disaster by the NGOs, which were backed by letters and comments from the public (ABIA 1991b, 1991c), and by many of the health professionals I interviewed. The relationship between government and non-government continued to sour. The years of 1990-91 were also some of the economically most afflicted times ever experienced by the Brazilian population; and those were the years when the AIDS crisis and its problems became more evident and demanded more action. By 1991, opposition between NGOs and the government had reached its most difficult levels.

It took time, changes in the Ministry of Health, international pressure, mounting evidence of the gravity of AIDS in Brazil, and its characteristics of medical and social emergency, for some convergence between the

governmental and non-governmental sector to occur. Towards the end of 1992 there were increasing levels of interaction between the two sectors in practical matters (see Schwarzstein 1992:3-4). The government had created an interface to negotiate with NGOs, and regularly called in consultants and experts from the NGO world. New concepts and strategies used by the government showed evidence of NGO influence: communication styles, publications, and interest in community-based organizations. Also, NGOs agreed to negotiate with the government about specific issues, some of them as critical as the support for vaccine development projects, or the allocation of World Bank special funds for AIDS prevention and care in Brazil.

Even though they did not converge in symbiotic harmony, the boundaries between the spheres of action of NGOs and of the government views became occasionally blurred. Many activists complained about confused identities when they started being funded by the World Bank via the government, and to see their organizations listed in government-published catalogues (Ministério da Saúde 1994a), or still to hear their own words of action borrowed by governmental-sponsored campaigns.⁸³ As some

⁸³The campaign that launched in early 1994, **Você precisa aprender a transar com a existência da AIDS**, was welcome by NGOs and the public. It included sketches with young people addressing candidly and in attractive ways the issues of safe sex and needle use.

organizations became locked into a survival strategy that brought them under governmental supervision, others moved into other sectors of intervention, such as applied or academic style social research on AIDS-related subjects -- sexuality, drug use, social meanings, and coping strategies. International commentators observed, catching a trend, that in the Tenth International Conference on AIDS, held in Yokohama, 1994, where Brazil had a strong visibility in many different sectors (e.g. Ministério da Saúde 1994b), the governmental booth looked like that of a NGO, whereas the booth of ABIA, the largest Brazilian AIDS-NGO, looked like an academic publishing house.⁸⁴

At that moment, the government had taken over much of the role of defining the world of NGOs -- a role that is not unrelated to the general movement towards emptying the state of its social functions by relying on their fulfillment by civil organizations, whether or not funded for that purpose. Handling in 1993 a U.S. \$125 million World Bank loan to fight AIDS in Brazil, matched by an equal amount from their own treasury, sometimes described as a total of 300 million (see Schwarzstein 1993a, ABIA

⁸⁴This observation was made by some of the international delegates to the conference and the view that "ABIA turned into a publishing house", instead of promoting the development of new AIDS therapies, was a remark made by ex-coordinator Walter Almeida, M.D., to **Jornal do Brasil**, March 18, 1995, in a interview about the potential of passive immunotherapy (based on the infusion of the plasma of long-term asymptomatic HIV positive people).

1993b), the government passed funds to different NGOs through cooperation projects. Many NGOs felt co-opted and tied up, limited to work on the one project for which they wrote the grant proposal, in a radical shift from their earlier partisan, community-serving, and alternative style in which international funds were allocated for loosely defined social goals. Like many others in Latin America, the AIDS NGOs in Brazil were in "their journey from protest to proposal" (Reily 1995:24), and did not feel completely at ease in their new social persona.

Calling in the **Pela VIDA** and **ABIA** coordinator Stalin Pedrosa to head the interface with the NGOs, the government took the role of surveying, counting and mapping the world of AIDS-NGOs in Brazil. In 1994, 140 NGOs serving AIDS were counted, 69 of them specifically defined around AIDS and/or human rights; among the others, 26 had religious denomination, 14 were women organizations, nine had gay denomination, four were from social movements, and the other four from health professionals movements (Ministério da Saúde 1994a:83). In 1993, 55 of those NGOs had joint projects with the government, ranging from U.S. \$6,000 to \$100,000. In 1994, there were 24 NGOs with new projects funded and 34 waiting for approval.

I argued in chapter 2 that one of the strongest components of the AIDS social movement in the U.S. was its interaction with the medical establishment and the ability to intervene in the previously inaccessible world of biomedical research. In Brazil, however, the expressive social movement responding to AIDS did not include much of that component. Before 1991, when both "Cadernos Pela VIDDA" were first published and public discussions on the local participation in HIV vaccine development were initiated, there were no traces of local "treatment activism." The changes this disease had brought into the doctor-patient interaction were restricted to a niche of educated, personally empowered middle class patients with access to information. Even if not exclusively, this was the bulk from where the new social character grew: the person with AIDS, fighting for his or her life and anxiously following the latest scientific news, transforming a "death-sentence" into a chronic condition and a demonstration of life; this had a special impact on a medical culture like the specialty of infectious disease, with its proverbial almighty aloofness and distance from the patient (see chapter 5).⁸⁵

⁸⁵The typical and poverty-related parasitic and infectious diseases required a brief treatment, for the patient either died quickly or got fully cured with no sequels. Doctors from that specialty often mentioned that they did not use to have any personal tie with the patients until they treated AIDS.

However, the intimacy with which North American activists worked through partnership/based innovation in science (chapter 2) was quite removed from Brazilian reality. The very relationship between a Brazilian PWA and a medical drug was mediated by a number of institutions, like laboratories, corporations, agencies, research centers, or information centers, that were located somewhere else and above, physically and politically, in the **First World**. People involved with AIDS in Brazil were by definition in a peripheral setting: they were in the **Third World**, removed from the centers of decision, doubly removed from the possibility of lobbying them directly. The ability to interfere in the core of the medical and scientific process was submerged in an ocean of basic and urgent difficulties. Long-approved drugs were still out of reach, too expensive or unavailable locally; there were not enough hospitals and hospital beds; many doctors and health professionals still refused to treat AIDS; families rejected people with AIDS, and an intense fear and prejudice dominated the society as a whole.

In this context, and according to their specific historical background, NGOs were oriented towards wider, more general questions. Like the agencies that supported them, Brazilian NGOs were concerned with the potential annihilation of human rights brought about by the prejudice that loaded the popular perception of AIDS, that

symbolically placed in the death row the people diagnosed with HIV antibodies, stripped them of their rights; as a response, community organizations fought for **solidarity**, defined as the "social vaccine against AIDS" (Daniel 1989).

For a number of years, no actual bridges or compatible knowledge between NGOs and the medical establishment were consistently pursued: NGOs worked on the area of human rights and general social issues, while the medical establishment produced and used its own knowledge. The "blood fight," which epitomizes an early interaction NGOs/government around a medical question, was conducted under such assumptions: having medical knowledge as a background, activists demanded action from the government to fulfill their right to have an uninfected blood supply.

As for other topics, there was no consensus among NGOs: for some, it was irrelevant to demand medical "quick-fix" solutions in such a devastated field of health; they preferred to work in the social and political sphere, demanding from the government a stronger and more effective intervention, involving the complete restructuring of the health care system. Other groups were oriented to work within the existing gaps, for example, to help people with AIDS find medication when the bureaucracy of public services delayed their treatment (Gurgel 1988; GAPA-RJ 1989). Until the question of the free distribution of AZT launched a public discussion in 1991, leading subsequently

to the publication of **Cadernos Pela VIDDA** (Gaspar 1992:2), there was not much room to question and interact with the medical establishment.

A turning point for the local increase in interaction between activists and the medical sphere coincided with the discussions of vaccine development, from 1991 on (see Belouqui 1994, Grupo Pela VIDDA et al. 1992, ONGS/AIDS do Brasil 1991, Schwarzstein 1993b, Sutmoller et al. 1994). The need for a community partnership for HIV vaccine development brought about a new style of action both to the medical establishment and to the activists. Unprepared for the social negotiation of their protocols, the medical researchers now had to face community representatives or NGOs; and NGOs had to learn the scientific details of the protocols they were involved in negotiating, which led to further mechanisms of differentiation. Turned into "experts" on the issue, some community leaders became invested with additional symbolic power.

The vaccine discussions brought together all different social aspects of AIDS: the tensions between government and NGOs, among NGOs, between educational and vaccine prevention, between spending quotas, between First and Third World, private industry and public cause.

The first public proposal to integrate Brazil into the global efforts to develop a HIV vaccine had been raised by WHO in 1991. Brazil combined an adequate epidemiological profile with the existence of a local scientific community able to contribute, and benefit from, the development of an AIDS vaccine. This suggestion, based on technical criteria, met the momentary situation in Brazil in the worst terms. The Minister of Health (Alceni Guerra, see above) and his AIDS office appointee, Eduardo Côrtes, were at the time severely criticized by the NGOs: the governmental AIDS budget had shrunk, the national program offices in Brasília were empty and unproductive, the "aggressive" educational campaign was considered faulty (ABIA 1991a, 1991b).

Also, a history of abusive medical experiments in the Third World, combined with a sophisticated anti-imperialist rhetoric, inflamed anger about the possibility of using Brazilian bodies as "guinea pigs" for international experiments (see ONGs/AIDS do Brasil 1991, Schwarzstein 1993b). There was no local history of treatment activism nor experience with volunteer participation in clinical trials. While U.S. activists fought for the possibility of being included in drug trials, often with dangerously toxic substances, Brazilian activists rejected the entire concept and mistrusted the system.

Moreover, the choice for prevention through education, rather than through vaccines, remained in the air waves

from the exalted moments of the "health revolution." The idea that "the vaccine already existed, and it was called solidarity" (Daniel 1989) had been broadcast throughout the activist networks. To go for a laboratory vaccine was somehow equivalent to acknowledging a defeat in the social fight against AIDS and the final acceptance of its medicalization.

Some of the points raised by vaccine development, such as the basic requirements for fair trials, as well as the production of community documents, launched awareness and interest in the community (see ONGs/AIDS 1991), so that it has been said that Brazilian "treatment activism" took its actual first steps around the question of vaccines (Grupo Pela VIDDA et al. 1992), following its incipient start around AZT.

The issue got full attention in 1992, after the new Health Minister Adib Jatene redesigned the public priorities for health in a way in which AIDS was given full attention. Lair Rodrigues was re-invested in the AIDS/STD office, now with a multidisciplinary staff and an interface with NGOs, anticipating the international mega-loan from the World Bank. The participation in vaccine trials was given a high priority, and was the subject of a number of documents and seminars (see Grupo Pela VIDDA et al. 1992). This might have been the moment of a major transformation but, both at a local and at an international level, history proved that it was not (yet?) the case.

The integration of different specialties, from virology to clinical medicine, immunology, epidemiology, statistics, behavioral sciences, and the diverse world of community representatives, was a difficult (and still on-going) component of the implementation of the steps necessary for the development of vaccine products. To add complexity there was competition between the different academic institutions in charge of the process, exacerbated by the promise of benefits like transference of technology, funds, and international connections brought by vaccine trials in a situation of scarce resources (see Marques 1993).

The combination of these multiple tensions characterizes the field of vaccine development at this moment in Brazil, where both WHO sponsored and NIH sponsored projects compete for cohort studies among similar populations, actually overlapping in cities like Rio. In the meantime, in the United States, in spite of better interactions between the different social actors involved, attempts for vaccine development experienced difficulties that led to the suspension of the "phase three" efficacy trials in 1994 (see Green 1995). This suspension directly affected the Brazilian situation; when developing countries are encouraged to test products rejected in the developed countries for reasons of potential danger and unsafety, the "guinea pig" specter rises naturally. The Fourth national

meetings of people living with AIDS, held in Rio in 1994, were largely focused on this problem and included guests from the relevant international and national institutions: WHO, Ministry of Health, Federal University of Rio de Janeiro, Federal University of Minas Gerais, University of São Paulo, FIOCRUZ, ACT UP-New York, ARCA-SIDA, as well as most Brazilian NGOs. No consensus is yet in sight, as there is none at the international level. The most noticeable trait of this process is its openness to public scrutiny.

To summarize, the social response to AIDS in Brazil should be analyzed both in terms of its sociological background (political, religious and academic) and its relationship to international responses to AIDS. These two elements, rather than the actual details of the medical and epidemiological problem, help us understand the particular forms and dynamics of AIDS organizations and AIDS action in Brazil.

As for the actual historical context, the coincidence between the early development of the epidemic and the generalized economic depression and institutional dismantlement following the dictatorship made AIDS in Brazil seem "The Worst AIDS on Earth," or made so, by the government's ineptitude (Ramos 1989). NGOs demanded the

most and the government responded the least. Inspired by the international movement and supported by international institutions, NGOs aspired to general health reform, if not a health revolution; the government could not but give scattered and short-term responses. After a period of difficult and feisty interaction, opponents became closer and better able to negotiate with one another around pragmatic issues, such as the management of the World Bank loan to fight AIDS in Brazil and the participation in the international vaccine trials. Many people and ideals were left out of the process: people who lost their lives to AIDS, who left disagreeing with the changing terms of action; ideals that were too broad to be met by the practicalities of human interaction and institutional competition, and which more easily turned into disenchantment. The history of social response to AIDS in Brazil, as in the world at large, is at once one of achievement, empowerment, learning and teaching, fundraising, research, publishing, media visibility, cosmopolitan links, rushing and anxiety, and one of losses, grief, and endless sorrows.

Chapter 5

**CENTRAL PROBLEMS IN A PERIPHERAL LANDSCAPE:
NEGOTIATING KNOWLEDGE AND TREATING AIDS
IN BRAZILIAN MEDICAL SETTINGS**

While the local NGOs, the government, and the international agencies were developing their various efforts to raise local awareness in order to prevent the spread of the epidemic in Brazil, the local hospitals, clinics, and medical offices faced a different aspect of AIDS: taking on the sickest of the already infected. While the different agencies worked with preventive messages, calls for solidarity and against prejudice, political issues, statistics, guidelines, and planning, hospitals and health personnel worked on a non-stop basis with people affected with *Pneumocystis pneumonia*, dying of respiratory failure, having toxoplasmosis seizures, meningitis, herpes zoster eruptions, assorted Kaposi sarcoma spots or cutaneous reactions to medication, loosing their sight with CMV infection, suffering from HIV dementia, disseminated thrush, herpes sores, and incurable wasting.

People came down with those symptoms outside the hospitals as well; they brought them to the different GAPAs, Pela VIDDA groups, ABIA, and other local associations just as they brought them to WHO, PWA Coalition, GMHC, ACT UP, AIDS Hilfe, and other AIDS

organizations in the world. To be intimate with this set of infections, face them, treat them, and talk about them became a part of living with AIDS. A strange and new specialized medical knowledge became part of many people's young adulthood in the 1980s and 1990s.

For those of us with no medical training who nonetheless became immersed in the world of AIDS, those diseases are not just commonplace references but are often associated with a name and a face, or several of them: Augusto went blind due to cytomegalovirus, the same infection that shrunk Ricardo's body to its bones; Isabel had cryptococcal meningitis and collapsed so rapidly; Pedro suffered the agony of non-Hodgkin lymphoma; Paulo was severely impaired with toxoplasmosis; Jaime died with the strange *Mycobacterium Avium Intracellular* before anyone could understand what was happening; Luis has such nerve damage due to Herpes Zoster that he can no longer put on his shirt; Neide wasted down to 55 pounds; John has tuberculosis and such severe thrush that he can hardly swallow his food. Also, a medicalized routine became part of so many of our lives: alarms ringing to time the intake of antiretrovirals, antifungals, nutrients, and all the mandatory pills that create the chronic inconvenience of being under AIDS medication. Prescription bottles fill the drawers. Some of us run around with a port on the forearm or chest, with a pierced catheter for the daily infusion of

gancyclovir, foscarnet, or intravenous zovirax. Some of the bedrooms and living rooms we inhabit turned into little hospitals where infusion poles and articulated beds became regular furniture. So many of us became nurses overnight.

Yet it is in the traditional hospital that all these elements converge. Under the same roof, side by side, sometimes in the same infirmary room where privacy is vaguely simulated with translucent curtains, the most afflicted and those with the most complex cases come together. They share the space with a medical staff that comes and goes, with a nursing staff that comes and goes, with a number of other personnel with whom they had no previous personal or emotional links. Internal and ambulatory care are provided, yet under severe limitations.

Under the globalizing experience of AIDS, which brings a common set of problems to central and peripheral hospitals alike, there are still heterogeneities that match a broader differentiation within the world system. In Brazilian hospitals, the limitations experienced by patients and health professionals are not exactly the same as those experienced North, in U.S. hospitals and medical offices.

In the United States, lack of knowledge about the new disease was the driving theme for struggle. It angered activists, mobilized scientists, and kept doctors and patients on edge. The social movement demanded government

money for AIDS research, fought for the release of drugs under trial or study, lobbied the science agencies for more drugs and more research, pressured the laboratories to cooperate, engaged in clinical trials, donated money to help speed up the process, created agencies to raise funds for AIDS; scientists and scientists-to-be engaged in the rapidly growing field of HIV research. Everybody wanted to know more. People from different areas found opportunities to build research careers by specializing in AIDS.

Activists, journalists and many of the public became amateur scientists constantly cruising the **Medline**, talking theory, negotiating trials, interpreting blood results, and creating personal and community strategies for treatment and prevention. Knowledge was the center around which everything else evolved: all was a matter of achieving, sharing, and applying knowledge in order to spare lives, prevent new infections, and avoid further agony.

In Brazil, the background scenario of deprivation was such that the AIDS crisis and its agendas differed in their terms, manner, and content. Knowledge about AIDS was proportionally less scarce than material resources. International information was available and circulated more easily than medicines and medical equipment. Once published in medical journals, new articles arrived almost immediately and circulated freely either in xeroxed form or synthesized in oral accounts. Yet, in the landscape of

scarcity and in a collapsing public network of medical care such as the one I observed in the late 1980s and early 1990s in Rio de Janeiro, drugs as simple and inexpensive as Bactrim might just not be available. The hospital might not carry them at the moment, and many patients could not afford to buy them in a drugstore. People with AIDS had to endure the pains of curable or preventable infections such as pneumonia because the existing treatments were not available in the public system nor was there money to buy them. In this respect, AIDS became like many other diseases of poverty, presenting its effects in inverse proportion to socio-economic well-being.

For those who were in charge of assisting AIDS in the hospital, the frustrations were doubled, for they increased with the fast pace of knowledge achievement. Not being able to administer some of the available and proven treatments was an additional stress for health care providers. As if it were not enough to manage the difficulties of treating AIDS, they had to see some CMV-infected patients go blind because there was no supply of Foscarnet, while others had bouts of pneumonia long after this infection became treatable and preventable with the administration of aerosol Pentamidine and oral Bactrim. In this context, knowledge about AIDS was a relatively abundant commodity: there was more information available than there was the possibility of applying it for for therapeutic purposes.

Information followed differentiated channels, stratified in the same way as contemporary Brazilian society. Some places within the medical care system were the best "doors" for the entry of new information; eventually, these were also the sites that distributed information to other local settings. As we have seen with the NGOs (chapter 4), some local sites were more cosmopolitan than others and had faster and more efficient access to the international circulation of knowledge. The best example is provided by the university hospitals, where medical students learn, young residents receive their training, specialists pursue their careers, and most medical research is conducted. In an attempt to understand whether those "doors" for the entry of international knowledge were two-way doors, that is, whether there was local research, and whether it was incorporated into the international production of AIDS research, I selected a university hospital in Rio de Janeiro as a primary field location.

Before describing the field setting, we should remember that Brazil is not a typically disenfranchised developing country but one with a contradictory tension between extra-developed sectors and underdeveloped ones, in

a First World/Third World combination. Medical settings are a mirror of that contradictory condition, both with regards to clinical assistance and to biomedical research. "Pockets of development" grow within a landscape of underdevelopment, in medicine as in other areas of society.

That contradiction matches the well-defined social stratification that broadly characterizes Brazilian society. Local elites live at the standard of the developed countries, with which they maintain regular contact,⁸⁶

⁸⁶Brazilian elites have always traveled abroad invoking cultural motivation and identity. In the 19th and first half of the 20th century they went to France, which they considered then to be the center of the civilized world. After the Second World War, the United States became the model of modernity and progress. Today it is common for the Brazilian middle classes to travel to New York and Miami just for shopping (see O'Dougherty 1995); in 1995 alone, 3 million Brazilians traveled abroad for shopping, most of them to the United States (*Veja* 1425:1, 44-50, January 3 1996); 91% of the Brazilian visiting the U.S. in 1995 declared that shopping was the primary purpose of their trip (*Veja* 1425:47); in the U.S. and in France, Brazilians were the tourist group who, after the Japanese, spent the most (*Veja* 1425:49). Cosmopolitanism, and particularly the exhibition of intimacy with European culture, are symbolic strategies for social differentiation adopted by the elites and upwardly mobile strata. Identification with European culture is used in a number of situations, which sometimes include the allocation of Brazil within the "western", developed sphere, rather than with the developing countries. An illustration may be given by the statement of a medical doctor from Rio who, when asked about his views on Brazil's situation within the world system, referred to his recent experience in Florence, Italy (where the International Conference on AIDS had taken place) as one of strong intimacy; the Renaissance art works were all immediately identified and experienced as a part of his self-identification, for they had been a central part of his education and enculturation process. He concluded, then, that Brazil was more of a Western than a Third World country.

while the masses live the standards of developing countries. When stratified by social class, the patterns of morbidity and mortality reflect the co-existence of two different countries, if not more than two (see Minayo 1995): a smaller one with the health afflictions of development, like heart disease, cancer, and also AIDS, and a larger one with the afflictions of underdevelopment, like infectious disease, child mortality, and again AIDS. When it comes to AIDS, both worlds converge and merge, as they do at a global level (see chapter 3). In a snappy description of the Brazilian health situation, ABIA reminds the reader that

among us, starvation goes hand-in-hand with top technology, producing all the evils of "backwardness" and of "progress." The absence of protein and the nervous ulcer are side-by-side in the national stomach; Chagas disease and sudden heart disease equally affect the Brazilian heart (ABIA 1988b)

If AIDS brought those two contrasting worlds together, they re-emerge separate and opposed with regard to access to treatment and medical care. An upper class gay man from Leblon⁸⁷ and a poor housewife from Baixada Fluminense,⁸⁸

⁸⁷ Leblon is one of the middle and upper class ocean front neighborhoods in Rio's **Zona Sul**, the city's fancier area. **Ipanema**, **Lagoa**, **Jardim Botânico**, and **Gávea**, are the other high class neighborhoods that share the views of **Lagoa Rodrigues de Freitas**, **Corcovado**, and the Atlantic Ocean. Also part of **Zona Sul** are the once fancy and now decadent beachfronts of **Copacabana** and **Leme**, as well as **Botafogo**, **Flamengo**, and, up the hill, **Laranjeiras** and **Cosme Velho**. Older neighborhoods constitute the downtown transition area (**Glória**, **Santa Teresa**, **Lapa**, **Fátima**, **Centro**) to the **Zona**

for example, may share the same AIDS-related illnesses, and they may even share the same infectious disease specialist who in the morning serves at a peripheral public hospital in Baixada and in the afternoon goes to a private office in Ipanema. Yet the experience of the disease is quite different for those two patients: if the hospital's pharmacy runs out its supply, she will not have the money to pay for the medicine, whatever its cost may be; he can fax the order to a network of air-stewards who will bring it from New York in the next 24 hours.

Their doctor travels daily between the two worlds: in the morning she cannot give more than a few minutes to each of the many patients that line up for hours after long bus rides from their distant homes; it is so difficult to get an appointment in the public hospital, which is free, that no one wants to miss it by being late. And there are always so many more people needing assistance than there is time

Norte which combines more conservative middle class neighborhoods like **Tijuca** and **Grajaú**, with popular working class and semi-suburbs like **São Cristóvão**, **Meier**, **Madureira** and **Bom Sucesso**, and a number of **favelas** (slums), like **Borel**, **Mangueira**, **Andaraí**. **Favelas** exist in most of the rocky hills scattered throughout the city, including Zona Sul, like **Pavão/Pavãozinho**, **Chapéu-Mangueira**, **Rocinha**, **Santa Marta**, **Tabajaras**; they contrast with the middle class **asfalto** (paved) neighborhoods.

⁸⁸**Baixada Fluminense** is an extensive **subúrbio** of Rio's North Zone. In Rio's urbanism, the periphery and suburban life is devaluated and left to those with lower incomes. The adjective **suburbano** (literally "suburban") is used as a derogatory term in **carioca** jargon.

to provide it. In the afternoon, the doctor does not endure that type of pressure, nor do her patients. The appointments run on a generous schedule in a comfortable office in an Ipanema high-rise. If the patient gets there early, he can sit on a sofa, listen to music, enjoy the paintings on the walls, or read the glossy magazines in the waiting room. When his appointment comes, he and the doctor can take their time to go through the medical aspects of the disease, discuss the suitable treatment, and even elaborate on the impact that AIDS has had on their lives. The other problems resolved, they are left with the limitations of knowledge about AIDS. As in the more cosmopolitan centers, they only have to wait for more scientific production and they follow avidly what is new and may work. They cooperate with each other in discussing and choosing possible treatment, and exchanging information about the latest ones. This doctor-patient encounter replicates much of what goes on in the upper fringes of New York, San Francisco, and Paris. In the "first-world environment" of private medical offices or in the expensive private hospitals and clinics, all that money can buy is supplied. The staff knows what is known elsewhere; the limits derive only from the fact that nowhere is there enough knowledge to prevent the AIDS related complications, which, at a biological level, devastate the lives of rich and poor alike.

Not all "pockets of development" refer to private practice, though, nor do all public services refer to the ultimate deprivation. A number of "islands of excellence" have been developed within the public sector, namely in the area of research. Private hospitals do not produce research, and private doctors, unless they are engaged in research somewhere else, use the knowledge that is produced outside and comes published in medical journals. Local scientific work is mostly produced in Federal or State-funded institutions. This is the combined result of a tradition of Federal and State investment in public research institutions and support from the military regime in the 1970s, whose ideology was grounded in the belief that growth and development could not be accomplished unless there were local competitive institutions of science and technology. As sociologist Regina Morel (1979) shows, the military governments in that decade adopted a policy of developing the local sectors of science and technology as part of its plan to fully modernize the country. At the expense of a growing external debt, the regime implemented a rapid modernization program that included heavy industry, nuclear power plants, transamazonian roads, state-of-the-art telecommunications systems, and also the creation, strengthening, or endowment of a number of research

agencies like CAPES and CNPq, as well as Federal Universities in several states.⁸⁹

Federal universities, which are tuition-free and open to all who pass the entry exam *vestibular*,⁹⁰ are today the most prestigious places to study, teach, and research; State universities are generally next in the hierarchy, and most private schools come last. Federally-funded research institutes, such as I.O.C./FIOCRUZ (see chapter 6), are also among the most prestigious institutions and have a solid international reputation. As mandated by the Constitution, research funds are almost exclusively handled by the federal agencies CAPES, CNPq, or the state agencies FAPERJ, and FAPESP. Federal University Hospitals, therefore, are the sites that bring together the highest research and prime medical care. It is there that the most prestigious clinicians and researchers concentrate, as they can pursue their scientific careers in those institutions.

⁸⁹Under the early military regimes research activities were seen as subversive, and a few of the biomedical researchers from FIOCRUZ were deprived of their professional licenses. However, the government headed by military president Médici changed policies towards FIOCRUZ and re-invested in it, allowing scientists to come back and funding laboratories and research activities.

⁹⁰This merit-oriented system hides the fact that, in order to be admitted into public universities, candidate students go through severe entry exams for which the average public education does not provide enough background. In order to be admitted, therefore, students go to private schools with high tuition at the elementary and secondary level.

Having analyzed the fermenting power of the interaction between activists and science institutions in the U.S. (chapter 2), and having asked whether the First World-Third World alliance promoted by WHO in the fight against AIDS was a new field for the fertile growth of new ideas (chapter 3), a university hospital from Rio seemed to be an ideal site to test my questions. Were there two-way interactions between local research settings and the central agencies of science, like WHO, the NIH, the Pasteur Institute, and major universities abroad? Were there innovative types of research protocols, like the ones developed by community research trials in the U.S.? When preparing my proposal, I assumed that the peripheral research settings from Rio had a potential for interaction parallel to that of the treatment-oriented activist groups from New York and San Francisco. In a vague way, global agencies assumed the existence of that revolutionary potential as well (e.g. Mann 1991). It remained to be seen whether the interactions actually produced any major change in scientific disciplines, both in the **form** of knowledge exchange and in the actual **contents** of scientific production.

As regards to **form**, the question was whether AIDS research brought actual transformations in the type of interactions between local researchers and mainstream,

centrally produced science, analogous to what had happened between treatment activists and scientists in the United States. Traditionally, peripheral sites had been voiceless in the production of science. More than one local scientist referred to the invisibility they had in international settings, often determined by prejudice, or by the system's inability to include their contribution.⁹¹

But medical patients had also been traditionally voiceless regarding their health. The feminist movement changed the order of things, and the fight against AIDS brought further transformations, with the self-empowerment of PWAs and the globalization of efforts against AIDS. Would there be also a new kind of "empowered peripheral researcher," akin to the recently empowered new patient, able to contribute to the whole picture of knowledge-making by contributing in his or her particular experience? This existence was implicit in the rhetoric of global agencies like WHO, who portrayed the world of AIDS knowledge production as one which included contributions from the entire world, as if every local experience was being accumulated in global data banks, incorporated in global

⁹¹"[They see us as] nothing, absolutely nothing", commented one Brazilian scientist, referring to the perception of centrally located researchers. "They were all surprised that I was a real researcher, not just a third world native", commented another one after a period abroad, exposing her own perception of how she was perceived by U.S. colleagues.

knowledge on AIDS, and subjected to multidirectional and democratic interchange. There were signs of a multi-sided activity coming from virtually everywhere, in oral communications and the posters presented in international forums and sponsored by WHO and other agencies. To explore the activities behind those results and the social interactions as lived in the local research settings that produced them was a subject for ethnographic research.

The **content** of the research problem unfolds in a number of directions and fields of enquiry. Clinical strategies were the area in which revolutionary AIDS treatment activism in the U.S. produced the most significant transformations and broke ground in the production of medical knowledge, with the creation of community clinical trials and the monitoring of biomedical research. They implied a new type of partnerships between the medical establishment and society. After a few years of intervention, activist groups in the U.S. extended their influence to basic science as well, and adopted another level of challenge to the task of interacting with the biomedical world with questions on AIDS pathogenesis and the role of HIV (e.g. Harrington 1992). This extension happened mostly after the struggles over treatment, drugs, and bureaucracy. Also, interactions of activists with mainstream science carried different meanings in different moments and for the different groups. They either involved

the negotiation of research priorities and questions or, in other cases, the radical challenge of accepted models, like dissent from the "HIV hypothesis" and the preference for a multicausal model that implied alternative therapeutic strategies.

From what I had seen, the areas of negotiation over knowledge about AIDS had a different profile in Brazil. There, one of the most sensitive areas of dissent and challenge, and also the most documented one, was epidemiology, which had been a minor issue in the United States. It had been discussed and social negotiation led to the correction of some epidemiological definitions, especially due to their impact in the access of specific groups to treatment, clinical trials and support programs. Yet, epidemiology was not a priority for discussion and transformative action in U.S. settings. In Brazil, however, it was the subject of passionate writing the part of social organizations and social researchers, who challenged the cultural assumptions behind the epidemiological model used to understand and frame AIDS (see Daniel 1985, Daniel and Parker 1990, 1993, Guimarães et al. 1988, Ramos 1990). While the social categories and cultural assumptions about behaviors that framed the epidemiology of AIDS were shared by mainstream science and activists in the U.S., in Brazil they were the object of radical critique and stimulated further research. Carmen Guimarães, Herbert Daniel, Silvia

Ramos, and Richard Parker noted the discrepancy between the epidemiological model for AIDS used internationally, and adopted by the local government, and the actual social, cultural, and thus epidemiological realities of AIDS in Brazil. That discrepancy, they argued, might alienate the population from following preventive messages, and therefore have a negative impact on efforts to contain the epidemic. Part of the purpose of the non-governmental organization ABIA was to provide basic social research on Brazilian sexuality and representations in order to redress that discrepancy, which, in their words, the government uncritically supported (see chapter 4). ABIA's preventive efforts clearly tried to move away from the stereotyped risk groups. They argued, and ethnographic observation confirmed, that the concept of "risk" was quite problematic in the local context. Spread by the media, it rapidly became loaded with stigma, as if to be considered "at risk" was derogatory in itself. To produce preventive messages, they either addressed the general public or, when targeting special groups, presented them in an original manner. For instance, men involved in sex with other men were targeted not as gay, or as bisexuals, because they would not identify themselves by those labels, but primarily as males involved in sexual acts (that happened to be with other males). Other target groups were construction workers, sailors, street youth, women, and youth.

The Brazilian government, accused by activists of adopting the international models too readily and uncritically, had in turn its own preferred area for the international negotiation of knowledge about AIDS: the **case definition**. Government officers from the AIDS/DST division in Brasília⁹² informed me about the role Brazil and other South American countries played in the revisions of the standard definition of an AIDS case proposed by the CDCs.⁹³ The revisions adopted by PAHO included pathologies that were more relevant to the Latin American health situation. The "Caracas Definition," establishing a number of points and scores for AIDS case definition, resulted from those joint efforts.

⁹²Brasília has been the capital of the country since 1960. Its creation from nothing and construction on the desert central plateau corresponded to the megalomaniacal dreams of a new civilization that characterized Brazilian politics after World War 2. Rio, the former capital, kept its aristocratic glamour while losing to Brasília decision making, administrative functions, and federal funding.

⁹³Pedro Chequer, personal communication, Brasília, August 1989. I would later discuss this issue with epidemiologist Maurício Peres and the AIDS program coordinator Celso Ramos Filho, at the Federal University hospital in Rio de Janeiro, in 1991. At that time, they had both been involved with the revisions on the standard case definition, working together with the CDC. The main piece synthesizing the work had been submitted, quoted a number of times as an unpublished manuscript, and yet not accepted for publication. Later on, a broader analysis comparing several AIDS case definitions with clinical cases was presented at the International Conference in Berlin, in 1993; the **Lancet** published a synthesis of the work in the form of a letter to the editor (Durovni et al. 1993).

What would be main area of negotiation, if any, within a clinical, teaching, and research site like a university hospital? Clinical aspects, as for the activists in the U.S.? Or, as the latter adopted in a later phase, problems related to basic science? Did the alternative immunology models I had learned from Brazilian scientists⁹⁴ provide the basis for alternative exploratory models on AIDS and possible therapies? I also wondered what influence the tradition of tropical medicine and the experience with infectious disease might have in the current understanding of AIDS. Would Brazilian doctors, like local NGOs, question the official epidemiology of AIDS? Or, like the government, the AIDS case definition?

⁹⁴An informal conversation with Brazilian immunologist Ana Faria in New York City helped me understand the scientific arguments against the limited character of contemporary models in virology and genetics, and further question the single agent theory of the etiology of AIDS. Further interviews with Brazilian immunologists made me realize that a number of them were working under an alternative paradigm, quite different from the dominant paradigm of invasions, assaults and counter-assaults, as well as foreign to the current obsession with molecular genetics (see chapter 6). This does not imply that there is some type of "native" model, but that locally they consider another paradigm as valid and root it in the early theories of Metchnikoff, holding that antibodies are not just "against" non-self but produced within the self as well. I came across the model again in Alfred Tauber's (1994) work on the philosophy of immunology.

The course of ethnographic research in a local setting shed light on the fractured nature of the "interactive" mode of producing knowledge about AIDS. There might have been a moment in the short and intense history of AIDS action where the global efforts against the epidemic suggested boundary breaking in a few different directions: generalized interactions between international partners, and generalized interactions between different social actors in the production of new knowledge about the epidemic. However, ethnographic research showed me that no undifferentiated locus of convergence and production of knowledge persisted long. Strong pressure for differentiation along disciplinary lines and professional roles neutralized the efforts for transdisciplinarity.

Nor is there a monolithic knowledge about AIDS, a local "product" negotiated as a whole in international settings; the existing on-going negotiation of aspects of knowledge accounts for a number of heterogeneities; its results do not have a stable, identifiable shape. One of the characteristics of that on-going process is that it tends to fracture along the lines of previously existing disciplines, despite the efforts to make bridges between the different kinds of knowledge and create a sort of transdisciplinary utopia, whose institutional manifestation is the creation of interdisciplinary teams.

The effort to attain transdisciplinary knowledge was present in the hospital setting I observed the most, which

had been conceived with an interdisciplinary format. The efforts to gather the different health professions and cross the disciplinary boundaries in order to respond to the questions and difficulties of AIDS suggested the possibility of a potentially new "medical culture" characterized by permanent interchange and boundary crossing. However, rather than in the ethereal space of transdisciplinarity, experience was capitalized within the grounded disciplinary and professional specialties. A plurality of networks, rather than a single corpus, interacted with the so-called global sphere. There were simultaneous and varied scopes of interaction which moved at different paces and acted upon different areas of knowledge, reproducing at an intra-unit level the fractures that in the external society already existed between different social forces, like the government, the NGOs, and the health services themselves.

Finally, another overwhelming fact affected the production of knowledge in a unit conceived to provide medical care, in a setting where scarcity and absence of quality services placed excessive demand on the university hospital. Drained by exhausting clinical work, health professionals often claimed that they did not have the time or the presence of mind to engage in research and turn observations and conclusions from clinical work with AIDS into relevant knowledge. Knowledge was secondary to

clinical work in the first place, and university hospital quality clinical work was subordinated to the overwhelming demand that the public system placed on the hospital. That theme would appear recurrently in interviews and statements provided by the hospital staff, particularly by doctors who felt divided between the demands of care providing and of research.

The clinical setting I chose as my main research site, the special AIDS unit of the University Hospital (HU) of the Federal University of Rio de Janeiro, was described by many as not of this world. Its remarkably good facilities were not representative of general conditions in the Brazilian health system. To compensate for this bias, I observed a few other outpatient and inpatient AIDS, STD, and infectious disease units in Rio and in Niterói, across the bay from downtown Rio. These sites included the more deprived University Hospital **Antônio Pedro** in Niterói, part of the **Universidade Federal Fluminense** (UFF); the old Hospital **Gaffrée e Guinle**, in the neighborhood of Tijuca, and attached to **Uni-Rio**; the outpatient Health Center in **Rua do Resende**, in the rundown neighborhood of Lapa, where prostitutes and transvestites do their street hustling; and the complex of **FIOCRUZ**, a large campus on **Avenida Brasil**

that houses the Oswaldo Cruz Institute for biomedical research, other research facilities, the National School of Public Health, and the landmark Hospital **Evandro Chagas**, created in the 1910s as a research hospital to study tropical infections while treating patients with them (Hospital Evandro Chagas 1990:1). I also included brief visits to some of the medical care and research centers of São Paulo, Bahia, and Belo Horizonte.

In Niterói I followed an outpatient service for a low income population, and was temporarily integrated into a team that provided medical care as part of medical training.⁹⁵ In FIOCRUZ, after auditing a course on tropical medicine, participating in public conferences and seminars and interviewing scientists in different research laboratories, I became (after fieldwork) involved with a research team as a consultant.⁹⁶ Mostly, though, I observed

⁹⁵This part of the research was accomplished due to the generous invitation of doctor Rosa Soares, also a professor of Clinical Medicine, whom I met at a training course in Tropical Medicine in FIOCRUZ. For a brief period I was part of her large team which included residents and medical students under training, as well as occasional specialists.

⁹⁶I got involved with the epidemiology unit at the hospital Evandro Chagas at the time the team tried to have an interface with community organizations for the purpose of evaluating a prevention program. This program was included as an ethical requirement within a larger multi-center project for a cohort study and epidemiological surveillance, funded by WHO, with the purpose of having indicators and instruments for future studies of efficacy in preventive vaccines. This was not a part of my own research.

the on-going processes as an anthropologist, with an eye on the "imponderabilia of daily life," the routine of social interaction, and the help of interview-scripts.

The AIDS care unit of **Fundão**, the popular name for the Hospital Universitário Clementino Fraga Filho (HU), part of the Federal University of Rio de Janeiro (UFRJ), is known as exceptional and un-representative of the decaying public health system. "**Não existe!**" ("it doesn't exist!"), people say to express how rare and unique the service is. Created in 1986/87 at a uniquely favorable moment⁹⁷ and with a special endowment and commitment to treat AIDS, the unit has been able to provide a quality of service that stands out in the poor landscape of public health services in Rio. The latter are most known for being on the verge of bankruptcy, if not already beyond it,⁹⁸ and are notorious

⁹⁷INAMPS, the centralized public health agency that owns and oversees several large hospitals, endowed the HU for the special AIDS Unit within DIP. At that moment, INAMPS was coordinated by progressive officers (sometimes referred to as the "medical left") who were committed to public health and who endorsed the need to publicly respond to AIDS. DIP was committed to providing assistance and maintained the 12 (later 18) beds guaranteed for AIDS. The program hired eight specialists, most of them out of the residence in DIP. The funds allocated to AIDS endowed the section with computers and laboratory facilities that would not have been possible otherwise.

⁹⁸The expression most commonly used to describe the health system at the time of my fieldwork was **total sucateamento**, that can be translated as "total trashing". Those were the years of the presidency of Fernando Collor, whose vague neoliberal project included the shrinking of government-based services, even though there was no free market-based economic vitality as a counterpart.

for their insufficiency of means, lack of resources, inability to respond efficiently to the increasing demand on health services, overworked and underpaid staff, decaying buildings, shortage of medication, stressful environment, and unsolvable social problems.

The University Hospital, **HU**, is seen itself as unreal, a somehow extraordinary building in a quite uncommon setting. Located on the **Fundão** island, the smaller of a set of islands in Guanabara Bay close to Avenida Brasil, in Rio's Zona Norte, near **Ilha do Governador** and between the slum complex **Nova Holanda/Favela da Maré**⁹⁹ and the international airport **Galeão**, this hospital is part of a modern set of high-rise buildings planned since the 1940s and built in the 1970s, during the military rule, as the campus of the Federal University. The buildings are set apart from one another at more than walking distance, in a desolated landscape, and are quite far from the Casbah-like urban effervescence of downtown Rio. The campus layout (like other federal universities from the period) was intended to serve the authoritarian regime's goal by preventing students from interacting outside class, and therefore excluding potentially leftist politics from academic life. The size and structure of the buildings

⁹⁹Literally "tide slum", due to its proximity to water and its former layout of palafite constructions. Palafites have now been replaced by sturdier housing.

reveals the megalomaniac ideology and dreams of unlimited growth that took shape in the 1940s and peaked with the military regime.

Projected on a larger scale than could ever be accomplished, with a total area of 220,000 square metros and 1,800 beds (Caldas 1990:17), the University Hospital remained unfinished for years, and was derogatorily seen as a "white elephant" (see Fraga 1990:34). The Federal University medical school was left for years without a clinical hospital of its own, while others with fewer resources or less prestige adopted more pragmatic and limited solutions: the State University UERJ got the "rejected" building of hospital **Pedro Ernesto** in Tijuca (Fraga 1990:26), the City University Uni-Rio used the century-old hospital **Gaffrée e Guinle**, also in Tijuca, and the public system INAMPS took the new building of the **Hospital da Lagoa**. Construction of the Hospital of Fundação resumed in the 1970s, halving the number of projected beds (Fraga 1990:63); forced to choose between resuming construction with demolition or just leaving entire aisles unused, the board went for the latter solution (Fraga 1990:28-29). To the present day, some floors are vacant and retain their bare cement structure. Occasionally, services that do not directly serve patients, like epidemiology, spread into unoccupied areas and "squat" in improvised offices by pulling electrical wire from the functioning

areas, laying carpets, putting in doors and windows, and bringing in desks, chairs and file cabinets, rather than waiting for the endless bureaucracies and shortage of resources that delay their official accommodation. In that respect, **HU** mirrors the condition of juxtaposed thirdworldliness and sophisticated high technology that Brazilians so often use to depict their country.

Located on the fifth floor, next to other DIP (infectious and parasitic diseases) services, and known as "5F", the special AIDS unit of the hospital is also one of the four National AIDS Reference Centers, together with the hospitals Emílio Ribas from São Paulo, Gaffrée e Guinle from Rio, and the research center FIOCRUZ, which is oriented to the laboratory component. Gathering a number of exceptional material and human resources,¹⁰⁰ the unit was created to provide first rate quality treatment to AIDS patients within the public system. Even though research was initially subordinated to medical care and diagnosis, its coordinators pushed for the involvement of other sectors of the university like microbiology, new-born care, or audiovisuals, in order to enhance the quality of work and knowledge produced, as well as to promote the engagement of

¹⁰⁰On top of the basic infrastructure of the University Hospital and its staff, the unit had a generous endowment provided by PETROBRAS, the national company for oil exploration and administration. That funding allowed the creation of special laboratories directed to enhance the quality of diagnosis.

the institution and its staff in internationally grounded research.

The pressure for clinical assistance is overwhelming nonetheless. The service's limited number of beds (originally 12, expanded to 18 with beds from neighboring DIP infirmaries) is avidly demanded by a growing number of patients and their relatives seeking both the quality of medical services and the free amenities provided by the unit. Patients have their own private room and bathroom and they are allowed a 24-hour visitor, a possibility rarely seen outside expensive private clinics, and a novelty that difficult for the public hospital staff to administer. Patients in 5F also have a leisure area with sofas and color TV, neat and recently painted walls and ceiling, and a pleasing atmosphere that contrasts sharply with the cramped and decaying wards of other hospitals.

The suspension of the chronic, third-world-like deprivation creates the possibility and conditions for the growth of patient self-empowerment. The health staff notices that the mindset and attitude towards the disease and towards themselves presented by the patients of 5F, exclusively for AIDS cases, contrasts with that presented by the patients whose beds are scattered among other infectious disease cases in the neighboring DIP wards 5C and 5D. Did this "empowerment" extend to the health workers, now involved in an international issue that

presses for the production of knowledge as hard as the patients demand clinical care? In some respects, this particular team seemed to be breaking ground. It was conceived according to the notion of integrated assistance with the aim of better addressing the multidimensional aspects of AIDS. The multi-professional team included full-time infectious disease specialists and residents, nurses and nurse aids, social workers, psychotherapists, psychiatrists, nutritionists; other specialists from the hospital staff, like dentists, ophthalmologists, gastroenterologists, dermatologists, pathologists, and pneumologists, served regularly in the unit.¹⁰¹

In order to work through the constant novelties of the epidemic which abruptly entered their lives, the health professionals gathered at a weekly team meeting that originally co-existed with the regular clinical meeting (see Souza 1988). They discussed the social and psychological aspects of each case, collectively trying to come up with a fair understanding of something about which they could not turn to older professionals or reference books for answers. They also examined their own problems as a team in the hard exercise of interdisciplinarity and teamwork. A quite novel experience, it did not always fully

¹⁰¹Some were actually hired and paid by DIP with the special endowment to treat AIDS, and ceded to the services of their specialty, as DIP did not need their full time dedication.

flow; implicit hierarchies of specialized knowledge and differential relationships with the patients co-existed with efforts to practice a "democratic" interdisciplinarity. Those early attempts to bridge the gaps of professional specialization with the exercise of interdisciplinarity give a sense of the transdisciplinary utopia that existed in that moment of the global AIDS struggle (see chapter 3). Captured in an unpublished manuscript (Souza 1988), those attempts show the difference between an idealized arena for the production of knowledge and the **de facto** situation.

By the time I interviewed health professionals and observed daily life at the unit in 1991, in its fourth year, AIDS was no longer a totally novel fact; anguish and questions had created patterns of personal and collective response, and the emergency character of the epidemic had been incorporated into a "normalized" routine. There was less need for intra-team interaction, as professional territories were more distinctly shaped. Professionals from the different areas already had an accumulated experience in the context of serving the AIDS unit. They constantly used and created original knowledge that contrasted with their previous experience as physicians, nurses, psychotherapists, and social workers. I interviewed them open-endedly and focused on their experience of treating AIDS and learning about it, as well as their ability to

integrate on the ground experience and empirical knowledge into the rapidly growing body of global knowledge about AIDS.¹⁰²

Could they convert their experience into communicable knowledge, validate it for universal use, make it **science**? Did they, based on local experience, formulate hypotheses, develop protocols, and produce articles for mainstream journals? Were they the social actors implicit in WHO assumptions on global exchanges, the local counterpart of that apparently global and multilateral venture of knowledge production?

The evolution of the dynamics of this unit shows a different picture. Throughout the years, as the novelty effect was eroded by the accumulation of experience, the pursuit of interdisciplinary exchanges faded. Health professionals retreated to their own specialties, as each developed its own sub-area of knowledge on AIDS. Spared from the additional effort of boundary-crossing and conceptual translation implied in a interdisciplinary venture, professionals preferred to specialize in their own subdiscipline, and interact with the international networks accordingly. It is therefore a multitude of networks that

¹⁰²I chose not to interview hospitalized patients, overburdened with the media's morbid eagerness to portray the "**aidético**." However, sometimes they wanted to give me their statements and have them tape-recorded. My interviews and informal interaction with people with AIDS in Brazil, though, happened mostly outside hospital settings.

interacts, at different paces and with varied scopes, at the so-called global level. For that reason, my field observations in the unit are organized according to professional specialties.

Every professional involved in AIDS care experienced a change from her or his previous work. Much of this transformation was related to the need to handle rapidly changing knowledge and eventually produce new knowledge. In the AIDS unit of **Fundão**, where the extreme deprivation of most Brazilian hospitals is, in some restricted areas, temporarily suspended, participation in the global production of knowledge might be expected from the team. At some level, this expectation is fulfilled: a significant number of the health professionals in the team participated in some sort of research, and many of them sent their findings to international conferences. Initially subordinated to medical care and diagnosis, research became increasingly important to the staff involved in the AIDS unit and opened horizons they had not foreseen to them when they chose to become infectious disease specialists. Before getting into medical knowledge, however, we should have an overview of the way the different professions working with AIDS were affected.

Social workers, for instance, experienced a change in the external recognition of their role. Trained for multiple tasks and to have a polyvalent job-description, as well as to move around different health services, the hospital-staff social workers allocated to the AIDS unit became central to the team work. Unlike with other diseases, or because of the special conditions of this unit, the team had an interest in issues that social workers managed; these included the better understanding of the patient's life beyond the hospital walls, as well as the establishment of a steady interface with their families and partners. In AIDS, the **knowledge of social aspects** become medically relevant and central for the management of clinical cases, as well as a help in defining the diagnosis, epidemiology, and in evaluating the conditions of home care and ambulatory prescriptions. With the integration of those notions into the unit's ideology, social workers' knowledge, once seen as residual and extra-medical, became relevant and necessary.¹⁰³

¹⁰³Sometimes the "residual" and "all-purpose" character of social workers' knowledge and role enrolled them to intervene when nobody else knew what to do. One social worker reported how she was called in to handle the case of a transvestite patient who had the civil and biological identity of a male yet social and psychological identity of a female, a fact that confused his/her allocation in the hospital wards and generated nervous reactions from an unfamiliar team.

The growth of social workers' professional visibility in the field of AIDS had several repercussions. They moved from a more pragmatic, quick-fix type of work into more engaged community participation as AIDS care providers, higher status among the hospital staff, and, furthermore, an intimacy with research that had not been in their professional horizon. The move from the more unstructured reality of all purpose patient care into the fully structured AIDS team was accompanied by a single topic specialization, described as a move "from the contact with several different pathologies... to living, breathing, sleeping, and waking up thinking about AIDS" (Teresa, 40).¹⁰⁴

The specialized knowledge of social workers was requested from several different fronts: the team, the patients and families with whom they acted as the hospital's interface, the community (either at an educational level or from other hospital teams seeking to exchange information and knowledge), and the international community, in which they participated actively sending papers on their particular work with patients they served in the hospital.

¹⁰⁴Unlike other sections of this work, all names of hospital personnel are pseudonyms. Recently, there has been a tendency to use the actual names of "informants" in order to acknowledge their contribution and often co-authorship. I adopted the procedure when interviewing scientists.

Like many other health professionals all over the country, social workers stressed the fact that AIDS brought growing experience at a painful cost. "Everyday you see a person dying...", they reminded me; they reported the despair and cumulative stress of closely observing the repeated death of patients whose demographic and social profiles were very similar to those of the health team; they had to discover new ways of negotiating problems and solutions within the families, who often behaved in unexpected ways;¹⁰⁵ they had to learn to deal closely and routinely with death, mourning, and terminal illness, as well as handling knowledge about sexuality in broader and more systematized ways. In the process, the specialization in AIDS brought them international visibility and a sense of belonging to the global community. The dramatic change included participating in international conferences with

¹⁰⁵Some chilling reports describe abandoned patients, whose families did not want them back. Most shocking for the social workers was that some mothers rejected their sons, contradicting the general belief of the solid character of the mother/child bond. Those cases were mentioned as exceptions rather than the norm; more often, mothers, partners, and other family members were constantly around the unit. There was also a famous case of a patient who had technical release from the hospital but could not be discharged because he had absolutely nowhere to go; his mother lived in the backlands of a northeastern state, far away from any type of medical care. He occupied a hospital bed for months with no technical need, and even appealed for help to Princess Diana of Wales who once paid a visit to the hospital unit.

papers, for which they developed original research and gained a new kind of recognition.

Like social workers, **psychologists** emphasized the learning experience they had with AIDS: both with patients and with the immersion in a fast-producing world of technical literature that opened new professional paths. Unlike social workers, psychologists did not report that their role had shifted towards the center of case management; it rather developed into a specialized niche. The assessment provided by psychologists and psychiatrists in teamwork was needed both for diagnosis and for some decisions about release or treatment; their main role, however, was a therapeutic one, assisting patients and helping them cope with a disease that brought together stigma, rejection, fears, anticipated mourning, guilt and blaming, experience of prejudice, and the need to address their own sexuality or their substance use. For many patients, the therapist was the only person to whom they could talk freely. With the therapist they worked through the complex coming to terms with themselves, with their condition, their sexuality, their body, their family, as well as their anger, guilt, and fear.

Psychotherapists report the experience of the first cases of AIDS they assisted within the hospital, before there were public and social efforts to raise awareness and before there were any community support groups for people

with AIDS. On top of the problems common to terminal cancer patients described in the literature, people with AIDS had the burden of the stigma attached to their disease; enhancing the fear of the unknown, stigma led to situations of panic. Guilt and fears of disclosure only worsened the already complex picture, and depression was a common result. The problems brought on by AIDS were a challenge for the psychologists and psychiatrists. Much of their early work in this context was exploratory and worked through in team meetings.

Part of the difficulty experienced by those early cases was related to the novelty and extreme panic and prejudice surrounding the disease. Infected transfusion recipients wanted to stress their "guilt-free" relationship with the disease, the burden of which they considered doubly unfair; speaking out against the blood transfusion system, the illegal commercialization of blood and the lack of surveillance, they had some instruments to institutionalize their revolt and anger. Those infected through sexual contact would seldom admit it, and were more prone to attribute their infection to transmission by female prostitutes than to sexual contact with other men. "By denying the means of transmission, they denied to themselves the fact of being sick," interpreted one psychologist, noting also that throughout the years the situation changed towards a clearer acceptance by patients of their own sexuality.

With the passing of the years and the accumulation of cases the novelty effect and the related panic diminished. Some aspects of the disease became more predictable; patterns emerged; the team grew in experience; public campaigns had some positive effect; anti-prejudice work was implemented by patient-based NGOs, which spread the word that it was possible to **live** with AIDS, instead of feeling only the internal time-bomb of a lethal disease; and the media took a less terroristic approach and gave AIDS a human face (see chapter 4). As an effect, the response of patients to the diagnosis became less dramatic, and psychotherapists were able to move forward to another level and work with them through the condition of living with AIDS, either as outpatients or at the hospital. Familiar with the establishment of links between psychological health and the immune functions suggested by activists based on empirical knowledge and discussed by some authors in academic journals (e.g. Baker 1991, Kaplan 1991), I asked some questions about the possible correlation of the two levels. Psychologists had an empirical "feel" that there was a correlation, but they would not turn it into a theory. "This is a damn virus," said one of them, holding HIV as responsible for most of the damage to the immune system of people with AIDS. Overemphasizing the power of the will to survive, as some activists did, was also a way of denying the condition of being sick with an infection that had no absolute cure.

Like other AIDS care providers, psychotherapists got burned out by their work. In a reflective, psychoanalytic approach to the impact of working with AIDS for the health care providers, they commented on their own distress. As one of them referred:

it seems like a cumulative and insidious type of stress. We can handle the difficulties of the clinical setting, give the patients their diagnosis, handle their reaction, help them sort things out and make their choices, come back home and still be human, learn a lot from the entire experience, grow scientifically and participate in the international community, but there is an insidious level of stress that we have not come to terms with yet. (Julio, 32)

Some noticed changes in their health patterns as effects of the new work; an excess of sleepiness, for instance, was interpreted as an effect of shifting the fears into the unconscious level.

Psychotherapists and psychiatrists handled a new type of knowledge, crafted by each of them with an idiosyncratic combination of empirical knowledge and contact with the international literature. They knew they could not expect their questions to be answered by supervisors with years of experience and accumulated knowledge; AIDS was too new and psychotherapists in the team were the very first in their profession to have direct contact with the local aspects of the disease. And the international literature did not cover the diversity of situations they faced.

They had different perspectives on how to make their unique experience available to others: some viewed training

interns as the best way of transmitting knowledge; some aimed to teach and lecture, which might provide them with professional growth while helping them to cope with the burn out of four years assisting hospitalized AIDS patients; and others were actively exploring ways to write papers and bring their particular findings to international forums, such as a discussion on the local adjustments of the scales that measure HIV dementia. As the local literacy level is different from that of the United States, where the scales were conceived, the instrument has to be correctly adapted in order to be used for the assessment of HIV dementia.

Nurses and **nurse-aids** managed the one-on-one physical tasks involved in AIDS care. Doing what most people outside the hospital would not do, like touching patients rejected by fears of contamination and helping them cope with multiple infections and vanishing strength in bedridden, dependent, and life-threatening situations, brought to some nurses a sense of professional accomplishment.¹⁰⁶ This was not so easy, as they had to endure on a daily basis the

¹⁰⁶A similar situation is describe by Peggy McGarrahan on a study in New York City nurses involved in AIDS assistance (McGarrahan 1992).

impact of difficult medical decisions with the patients.¹⁰⁷ Rarely indulging in public visibility or research-oriented growth,¹⁰⁸ nurses stuck to their technical and vocational roles as health care providers.¹⁰⁹ Crushed between an outside world of prejudice and morbid curiosity about AIDS and their performance as hospital nurses, they were the most susceptible to professional burn-out and asked for more frequent replacement. Nurse-aids, handling the most "risky" activities which involve needle puncturing and body fluids, and having the least professional reward, felt the

¹⁰⁷Some hospital staff used the stereotyped nuclear family metaphors to describe nurses as the "mothers" (some were male) who handled the hardships of domestic life while doctors were the decision-making "fathers" (they had a balanced female/male ratio) who did not need to be there to handle the impact of those decisions. For a grounded discussion on the medical decisions and confidence, see Bauman et al. (1991)

¹⁰⁸In Brazil, nursing is considered a professional/technical training rather than an academic one

¹⁰⁹During my research I could observe the consequences of, and resistance to, the introduction of new AIDS therapies that involved an extra amount of work for the nurses. At some point in 1989-90 the government had distributed equipment for the administration of aerosol pentamidine, a powerful preventive for AIDS-related pneumonia (see chapter 2). Its administration, however, involved a number of extra hours of nurse work and more flexibility in the house rules. A nurse with a special commitment to AIDS therapies put in the energy and work for some time. After he left, nobody had an interest in it or was available to administer this life saving, yet non-mandatory procedure. Had there been an extra incentive, such as greater involvement of the nurses in the overall project of AIDS care, a doctor commented, things might not have become so difficult and contrary to the interests of the patient.

most vulnerable and most often asked to serve in other sectors.

In spite of all the efforts towards interdisciplinarity and teamwork, **doctors** were **special**. In the patients' hierarchical representations, doctors were above all, and therefore entitled to the last and most revered word. Other health professionals complained that they sometimes had to involve a physician in order to communicate efficiently with the patient, even if the message was related to nutrition, to psychological issues, or to other non-medical specialties. Interdisciplinarity was a challenge lived differently by each of the elements of the medical team I met. While some regarded the experience as of growth not only for themselves but for the practice of medicine and for the patients' well-being, others behaved as if something was in the way, delaying their work as physicians.

Who were the doctors who rapidly became specialists in a disease that did not exist at all when they went through medical school? Which type of "medical culture" did they represent? How did they stand within the symbolic hierarchies that organize the medical system? As the epidemic and its effects are constantly changing, it is still early to venture generalizations about this subspecialty developed specifically to treat AIDS. The

ethnography and micro-history of particular settings, such as the one in question, may however contribute to the understanding of general questions.

In the unit I observed, as well as in many other sites in Brazil and in the world, the "AIDS doctors" inherited the experience of the specialty most of them had been trained in **infectologia** (literally infectology, or infectious disease specialty), also referred to as **DIP** (for **Doenças Infecciosas e Parasitárias**, Parasitic and Infectious Diseases). This allocation is a matter of debate and sometimes it is challenged by other specialties. Dermatologists, who treated the generic sexually transmitted diseases and syphilis, examined some of the early cases of AIDS and also saw it as "their" specialty. In some services, the new disease was assigned to Oncology; after all, its first characterization had been as Kaposi Sarcoma. Internal Medicine claimed that there is no particular reason to treat AIDS separately and within specialties (e.g. Côrtes 1991). AIDS patients could be treated by generalists with consulting specialists; by the same logic, AIDS hospitalizations should be scattered, rather than clustered in special units.¹¹⁰

¹¹⁰The debate also took place in the United States. When a AIDS ward was projected for San Francisco General Hospital, the argument was that AIDS required a new specialty that could treat the complexity of simultaneous infections; the counter-argument was that a separate ward would be like a leper-house, duplicating the stigma that there was in the outside world (see Shilts 1987).

The allocation of AIDS within **DIP** services had a tremendous impact on them. This change was locally experienced with some degree of paradox. Most **DIP** doctors who became AIDS specialists regarded the allocation as natural and inevitable. As an "infection surrounded by infections," they noted, AIDS should be treated by those who have built their medical expertise on infectious diseases. Also, the tendency to emphasize scientific research within their specialty (see chapter 6) seemed to combine harmoniously with the fast-growing research side of the field of AIDS. Also, they claimed that they were the ones who took care of the initial cases, when it was not yet clear that the epidemic was there to stay and that it would be a vehicle for research funds and professional growth. Accustomed to the generic unattractive and life-threatening patient, **DIP** doctors took the first AIDS cases in a time when, they made a point of noting, no one else would accept that challenge.

On the other hand, they pointed out, a disease like AIDS was precisely what they had tried to avoid when they chose the infectious disease specialty. They had been lured by the efficient and definitive type of intervention that medicine could have on infectious diseases. They were attracted by the feeling of "omnipotence" that the specialty had brought them. "We felt almighty, omnipotent,

when we actually **cured** someone who seemed to be dying," they repeatedly reported:

You see a patient one day trembling in seizures, everybody thinks he is going to die, and you diagnose meningitis, or toxoplasmosis, and you give the correct medicine, and soon he is out of the hospital, as if nothing happened... that is very rewarding... your knowledge brings omnipotence... (Jorge, 30)

They could cure. They could have a word in the life-or-death game. They could bring to full health a patient dying with meningitis, leptospirosis, or malaria. In their accounts, the DIP patient was the one who either died fast or got cured. Their specialized knowledge provided them with the ability to produce a correct diagnosis, an adequate treatment, and therefore a cure; the patient was supposed to leave free of symptoms and not return to the hospital, at least with the same ailment.¹¹¹ They knew that their colleagues in charge of cancer or kidney disease had a different experience, with little to provide their own ailing patients. And that was precisely what those who chose DIP were running away from: the chronic patient, the person whom they could not cure and whose slow agony they had to share without being able to revert it.

¹¹¹Although that representation is not totally accurate -- for instance, patients with hepatitis-B return to the infectious disease ambulatory clinic many times and may neither get cured nor die -- it is part of the inner core of beliefs or DIP myths that lead young medical students or residents to chose the specialty.

AIDS disrupted their world and their professional self-perception. Omnipotence gave place to impotence, humbleness, and a new kind of acceptance of their limitations. The impersonal and nameless patient, identified as the carrier of a known infection, gave place to a complex, demanding and needy patient whose return to the hospital was almost guaranteed. The short term and superficial interaction with patients with acute infections gave place to a longer and often deeply-rooted and engaged doctor-patient bond, involving new challenges for both parties, which included the search for new elements of knowledge. Issues that had never been addressed in medical textbooks and courses, such as sexuality, drug use habits, or intra-domestic relationships, turned out to be central for case management and rapport. Doctors were faced with an entire new agenda of things to learn.

Also, the epidemic reverberated into several levels of their lives and identities. The new patients had a social and demographic profile which was much closer to that of the doctors than the traditional low-literacy and low-income DIP patient used to have. That fact brought the epidemic closer to the health professional and had a further impact on the subculture of the specialty. In a previously unknown way, the problematic of the patient reverberated in the physician's identity: "it could be my father, my brother, myself," some pointed out. Age, social

background, and the fact of being sexually active, all brought the patients closer to the doctors.¹¹² The detached, aseptic and hierarchical doctor/patient relationship gave way to a constant interaction with circulating questions. The fact that many doctors opened private offices, a possibility they did not have as DIP specialists, is a sign of the shifting character of the culture of that medical specialty in the context of AIDS. Interaction with people with AIDS and AIDS organizations changed the lives and perspectives of a number of doctors as well; the learning of gay lifestyles and the forced intimacy with declining health in the prime of life, surrounded by social prejudice, cracked the uptight professionalism that characterized many of these MDs. The forced cosmopolitanism brought by frequent traveling for international AIDS conferences (see chapter 3) and

¹¹²Female physicians tended to express it as "it could be me" more easily than their male colleagues who, like most of the society, felt threatened by the symbolic sexual implications of being male and having AIDS; they would more often go for "it could be my brother". As the number of women with AIDS in the wards increased and the stereotype of limited risk-groups faded, health professionals felt increasingly vulnerable and closer to the core of the disease. Not because of the fear of contamination, as it had occurred years before with the very first cases, and as discussed in the international literature (Dworkin et al. 1991), but by feeling how close to the epicenter they were due to their own age group and sexually active life-style. Installed in the unconscious and coming to consciousness every once in a while, whether in dreams, conversations, or therapy, that feeling and related fears were kept under control for better professional performance as, in the wards, they were the healers and not the sufferers.

workshops, the fast growing international networks of AIDS research, and the overgrown amount of circulating funds for international AIDS work, also had an impact in the personal and professional lives of those specialists, and ultimately helped in the transformation of the specialty from its previous low-profile status to its present high visibility.

The group I followed was a special one. In addition to the previously existing DIP staff, the AIDS unit created in 1987 had hired in eight specialists who had just finished their medical residence. That group of people had chosen infectious disease before they had contact with AIDS; they had seen their first cases during the residence or right afterwards. They were in the transitional moment where most of the impact was felt; the generation that followed them would learn about AIDS while still in medical school, while the older one had specialized in other infections before this epidemic was around. The intermediate group became the core of local specialists on AIDS. They were young, in their late twenties to mid-thirties, at the age of career launching, and many of them were working at that time on their Master's degree in Tropical Medicine or Infectious Diseases. Becoming specialists at an early age, some would later engage in international research careers, public administration, or open a private office -- rarely an option for infectious disease doctors, but a demand for those who became specialists on AIDS.

AIDS entered their lives very rapidly. Remembering their first experience, some go back to the first cases in the unit in 1985. There were earlier identified cases in São Paulo, and some of the unit doctors who did their residence in that city recalled their first acquaintance with AIDS while there.

I did my residence in Emílio Ribas, which is the large hospital in São Paulo where all the infectious diseases go. It is known for people crossing the street to the opposite sidewalk, when they pass by, for fear of catching an infection... I saw the first cases of AIDS there... we did not really know what it was about... (Cecília, 29)

In the beginning we used all the paraphernalia, we used surgical masks, we used gloves, long hospital gaunts, all those things ... we did not know much about in-hospital transmission... my family teased me saying that I was **grupo de risco**, I used to say I was of **grupo de arrisco**, I took the risks... then we relaxed with the procedures, there were not always gloves and masks to use, then we got used to leaving them behind, we lost the fears... (Jorge, 30)

Some got acquainted with the disease during their residence in Rio, in this or in other hospitals:

[the supervisor] called me to go see this case, it was a case of immune breakdown, the patient had all these different infections... it was the first case of AIDS I saw, we thought then as if it were a rare disease, not as something that was going to come and stay with us the way it did... (Mariza, 30)

One doctor commented that the very first patient she got as a resident, back in 1985/86, was a person with AIDS, so that this disease became immediately incorporated into her professional experience within the specialty.

Combining an accumulated number of cases with rising public awareness and political momentum, the program on SIDA/AIDS launched in the hospital in 1987 was mostly oriented towards diagnosis and medical care. From the very nature of the endeavor, handling new knowledge was one of its daily basis tasks. Unlike other infectious diseases, which were fully characterized in textbooks, studied in medical courses, and supervised by the elderly specialists, everything about AIDS was new. Textbooks had limited and insufficient information. The older staff members, with greater clinical experience and commonsense, did not know the details of the new disease. The team had to break ground, seek knowledge, and be constantly creative.

Asked about their sources of information on AIDS, the team referred to medical journals and peer interaction as the central strategies for keeping up with knowledge. Traditional clinical and infectious disease journals were the most quoted for their updating: **Annals of Internal Medicine, Lancet, New England Journal of Medicine, British Journal of Medicine, Journal of the American Medical Association (JAMA), Journal of Infectious Diseases, and Reviews on Infectious Diseases**. In addition to these, though a less common reference, there were two publications specifically on AIDS, the **Journal of Acquired Immune Deficiencies** and **AIDS Research**. Less quoted, but referred to by some, were general science journals like **Nature** and

Science. The degree of intimacy with the journals varied within the team: some had personal subscriptions, some consulted them actively and on a regular basis, and some ran after specific articles mentioned by colleagues. Between the library at UFRJ and the library of FIOCRUZ, nearby on Avenida Brasil and handy to those who either worked there or went there for graduate work in Tropical Medicine, most journals were accessible. Moreover, there were organized groups for the xeroxing of relevant articles, so that new information could be shared rapidly and efficiently. The usual scarcity that affects researchers in peripheral settings was largely compensated by mechanisms that made information easily available. Information, at least as published in mainstream medical journals, was abundant and generously shared. Alternative information, such as that handled by international PWA groups and by local NGOs, was less accessible to the team. Even though some of the health professionals read the NGOs newsletters or participated in some of their activities, those organizations did not provide a source of regular information that mattered.¹¹³

¹¹³It should be noted that just before the period of my interviews (1991) there had been an incident which had embittered many of the team health professionals against one particular NGO and extended to the whole category. A more self-empowered, college-educated member of GAPARJ was admitted to the emergency-room and waited there for several days before he got a regular hospital bed; shocked by the poor conditions, his organization protested in the newspapers and targeted that particular hospital. The situation was however quite current, and the health team

A number of my questions asked the extent to which the mainstream, American- and British- published knowledge fitted the local clinical cases adequately. I had been told by government officers that there were some inadequacies in the criteria for clinical case definition. Also, acquainted with the social and activist critique of the "imported models," I was interested in knowing if there was any on-the-ground challenge to the prevailing clinical knowledge on AIDS. For that issue, I persisted on several points: how often did they face "unexpected situations" and what did they do about their doubts; what might be particular and idiosyncratic about Brazilian AIDS; what should the priorities for research be; had they turned their acquired experience into communicable knowledge, either by articles, communications in congresses, teaching, and social intervention?

Most of my physician interviewees acknowledged that they had to face new situations almost on a daily basis, and that a lot of creativity was involved on the process. However, the knowledge thereby created was not treated as publishable, interchangeable knowledge; it was taken as

was all but tired of fighting for more resources in order to improve treatment. Upset at being targeted by a NGO that should in their view be targeting the government for better health care, doctors were at that moment distrustful of civil organizations, which they viewed as concerned with their own members' well being rather than with general social causes.

empirical, on-site and orally transmissible knowledge. Asked whether their "local knowledge" could be converted into research hypotheses and communicable science, for it often led to legitimate and fundamental research questions, most of my interviewees expressed uneasiness with the world of research. Combined with material obstacles, like lack of money, time, and infrastructure, there were cultural and psychological obstacles preventing them from making science and being full actors in the global production of knowledge about AIDS. They had not been trained in medical school to handle research, they did not know the procedures, they were unfamiliar with research design and methodology, they did not feel comfortable writing English (by and large the medical research language); moreover, a background ideology established a sharp separation between their immediate reality in a third world setting and the "first-world style" of the medical journals like **New England Journal of Medicine**. Some of them referred to cases where a researcher had gone through the pains of collecting data in spite of all the difficulties and obstacles, just to have, in the end, the piece rejected for not meeting the criteria of the journal; that kind of example was used to justify the lack of motivation to be involved with research.¹¹⁴ For many,

¹¹⁴Some used the expressive image of **morrer na praia** (literally, to die at the beach), meaning being almost there after a long struggle and succumbing at the very last minute, to describe the situations when after so much work, and being almost there, one would not go through.

however, there were more basic problems such as the pure lack of time and exhaustion from the draining clinical work.

Not all the interviewees were uneasy with research, though, and some had spent time doing graduate work abroad, or planned to do so in the future. A period of scholarship abroad tended to eliminate a number of myths, namely the self-perception of being unable to participate in the world of science making. Having a local laboratory structure and a full-time team with exceptional conditions, and counting on the worldwide flow of research funds for AIDS, some foresaw the feasibility of local research. They acknowledged, however, that they could not assume that their unit was "an isolated island of excellence while outside chaos is installed" (Mariza, 30). A lot of other elements, from low wages to the stressful pressure of clinical work, and the absence of a steady infrastructure, prevented the flourishing of research. There was always that background noise of being in the third world while attempting to do some "first-world-like" work, always under the threat of failure or sabotage.

Partnerships with centers of research in developed countries represented an alternative to the more complex endeavor of conceiving original research. Timidly, those became a part of the unit's life, even though it took some

extra work to persuade the central agencies or universities that actually do research to establish real partnerships with them. One coordinator of research once confessed that after frustrating attempts to engage "first world" agencies in local research, he concluded that they were more comfortable just donating funds in a patronizing way, than establishing a dialogical relationship with local researchers. After negotiation, however, some protocols were developed and brought in more funds, research energy, and space in publications.

In the end, production depended on a complex negotiating process; as a component of multicenter studies, data collecting was more easily fed into the mainstream, even though in a quite different manner than I had hypothesized when envisaging the scenario of a paradigm shift in a global setting. Also, developing research on issues of less interest abroad and more feasible locally was another way of obtaining visibility for local research. Some pieces could even get into mainstream journals (e.g. Schechter et al. 1994); and many got into the annals of the International Conferences on AIDS, whose Books of Abstracts became sources of reference as well (e.g. Bolton and Orozco 1994).

If I was expecting an ocean of local creativity pursuing the most varied hypotheses on AIDS etiology and pathogenesis, as well as on local clinical and

epidemiological specificities of AIDS, if not pathbreaking research on basic immunology, I could but realize my own naïveté. This was not the site for it. Their participation was bound to add bits and pieces to a large building whose architecture had been defined elsewhere.¹¹⁵

Overburdened by clinical work, physicians hardly had any time to go after research hypotheses. Having access to abundant, but monolithic knowledge on AIDS, they would not dare waste time pursuing speculative alternative models. They did not feel entitled or empowered for the purpose. Contrary to New York AIDS activists who were exposed to a number of diverse informational sources and whose basic attitude was tempered by mistrust of the science agencies, and contrary to Brazilian activists who operated from a basic opposition to the government, the local doctors I interacted with were tied to a single source of knowledge, that of mainstream journals, and they depended on it to do their best at what was their priority, treating people with AIDS.

¹¹⁵The metaphor of "the little brick in the wall" was often used by local researchers to describe their own participation on the collective process of producing knowledge on AIDS. Very different, a non-clinical researcher once described the aim of a scientist as to "open windows in the walls", that is, shed new light on the issues, produce a leap in knowledge; "then", she went on "there are always people engaged in putting those little bricks that close the window entirely, so that you have to look for where to open a new window".

As an example I pursued the history of their personal understanding of one of the questions that is revealing about the processes of debate, dissent, and consensus achievement: was HIV the single cause for AIDS or should its etiology be thought in terms of multiple factors? The question had already been discussed by social commentary (e.g. Moraes and Carrara 1985a, Patton 1990). I asked doctors about a co-factorial hypothesis versus the prevailing unifactorial hypothesis, centered on HIV. The question was irrelevant for a number of them, as their first contact with AIDS dated from a time when the prevailing model had been established. They had not followed the Greenwich Village debates (chapter 2) on possible etiologies, and most of them were persuaded by the viral hypothesis. For those who remember reading early articles on AIDS, before LAV and HTLV-III were isolated, the viral hypothesis seemed from the beginning the most plausible one, due to the similitudes between AIDS and hepatitis B.

When I read the first articles it immediately seemed to me that it was an infectious disease, most likely virus-related. Its epidemiology was too similar to hepatitis B. (André, 37)

I was still a student, and we had this science conference of the medial students, and I remember we debated heavily, some people thought AIDS was just homophobic propaganda from *Globo*, but it clearly seemed to me that there was a transmissible disease that might affect the entire population... (João, 34)

I did not risk saying it was a retrovirus, I could not have known, but I was quite clear it had to be an infectious agent, most likely a virus, a new one... When Markito [the first publicized case of AIDS in Brazil] died, there were still people that thought that AIDS affected homosexuals because they took hormones and that type of thing... I always thought it should be a new virus... (Claudio, 45)

However, some raised a few questions on the role given to the virus in the full explanation of AIDS.

There have to be co-factors! How do you explain that some people get sick after one year of transfusion and others remain healthy for many years? (Heitor, 35)

Supportive of seeing more research on complex immunological aspects of AIDS, some of these doctors lamented the fact that immunological research is even more expensive than virological characterization and studies of seroprevalence.

On one thing most agreed: that clinical research and epidemiological surveillance were the most "do-able." If anything, Brazilian AIDS would differ from the international literature in that some local infections, such as tuberculosis, would be more prevalent. Some commentators noted that even the tuberculosis research, which was of genuine local interest, was being carried out in "first world terms," involving expensive petri cultures and assays instead of the more accessible differential diagnosis method. Research on more affordable means of

diagnosis should therefore be a priority, and the one way in which Brazil could contribute to global health care.

As for epidemiology, they admitted that there might be some originality in the local forms of transmission, some hardly conceptualized local patterns of sexuality. That did not mean they agreed with the social commentary on Brazilian sexual culture that was being reproduced in academic books and even in the popular media at the time.¹¹⁶ Nor did they accept what was then one of the favorite topics for the media, the "Africanization" of Brazilian AIDS,¹¹⁷ a lead that was supposed to synthesize the concepts of heterosexualization of the transmission pattern, based on the WHO-defined pattern II (Africa and the Caribbean), and pauperization of the epidemic (see Kalichman 1994).

Even though they treated an increasing number of women with AIDS, gay men remained the majority of cases. The original epidemiological pattern, described as similar to the United States, or "pattern I," remained valid. They challenged, however, the pertinence of the notion of "risk

¹¹⁶That included featuring anthropologist Richard Parker, a Berkeley graduate and professor in UERJ, in T.V. shows and popular magazines, as well as the rapid translation of his book **Bodies, Pleasures and Passions** (Parker 1991a) into **Corpos, Prazeres e Paixões** (Parker 1991b) by a popular press.

¹¹⁷E.g. **Globo**, 11.5.1987, and 4.13.1989; **Folha de São Paulo**, 8.8.1991, and 10.3.1991.

groups." It might have accommodated the initial analysis for epidemiological surveillance, but it did not describe what mattered, that is, behaviors and acts of risk. In their initial contact with the disease, when the risk category was a part of the definition of an AIDS case, they were quite concerned to find the risk group of the patient; afterwards, they stopped considering it as central and often left the identification of risk untended. At the time of my interviews, the AIDS epidemiology division of the board of health was concerned with the fact that the category of "unknown risk" was increasing, probably as an effect of doctors' disregard for the problem. In fact, as far as I could determine, AIDS physicians experienced a sort of split feeling between their achieved lack of interest in the way the patients were infected, on the one hand, and, on the other hand, their responsibilities towards public health and accurate reporting.

Within this diversity of quasi-contributions, only a few dissenting views became pieces of knowledge, and even fewer were incorporated into international knowledge. The most important were probably those related to tuberculosis and its relevance in the context of AIDS, and the revisions in the AIDS case definition. Yet, no major challenges to

the mainstream production on AIDS came from the clinical settings I followed. The impact of the clinical aspects of the disease was too distressing, the pace of production of new knowledge in the mainstream international journals was just too overwhelming, and the self-evaluation of those who served at those sites was that they could not compete with that production except as collaborators. Most of what could be found was what was known; as one doctor once pointed out, "we can only find what we were looking for."

Sometimes, after new international findings changed the way of perceiving an issue, they could trace back their own perception of it, unformulated as an alternative, and only kept for personal reflection. Even under those circumstances, ideas for innovative research were around, but they were not suited to being turned into research, at least not at that time and place.

The two-way interaction and the global circulation of information, as found in a local setting, had an asymmetrical shape. Information abounded, but flows were rather unidirectional. International channels filtered information into the stabilized, approved findings of science; debates prior to consensus-achieving could hardly be followed, much less integrated. Flowing from centers to peripheries, information became monolithic and uniform; responses to it could only be made in the very same terms, or they would not be heard. As a consequence, the flows

from peripheral settings to the centers were few and quite monolithic. The global venture of WHO might not have a counterpart in medical research, or at least not yet. The empowered peripheral researcher had not yet entered the field.

It was further away from the stressful and constantly draining field of AIDS, or at least further away from the clinical care, that I would find the equivalent to the imagined empowered peripheral researcher. It was close enough to AIDS, but not quite within it, in the surrounding fields where knowledge is produced: in research laboratories in immunology and infectious diseases, in epidemiology, in the social sciences. With that finding we get a sense of how the massive globalizing process may have opened new avenues of dialogue, but not all those that it might. Some of them deserve further attention.

Chapter 6

**WAR METAPHORS IN GERM THEORY AND IMMUNOLOGY:
IN SEARCH OF A NEW PARADIGM**

In the preceding chapters I tried to avoid the exhausting repetition of the warfare imagery that pervades the field of AIDS, and that so often turns texts into assemblages of military reports and wargame bites. Still, the "report from war" genre would well match the feelings of devastation and loss experienced with AIDS, for it seems so much like a real war: bodies keep falling, losses are counted, and no one knows when it will be over. Yet the warfare vocabulary and images used for AIDS go beyond the expression of feelings of devastation and collective loss. They are deeply settled in the different layers of the field, from macro politics and policies to the microscopic level of biological interaction between cells and viruses.

Warfare is the central paradigm from which every thing else in the field derives. Action related to AIDS is referred as a global **fight**. "War" does just not stand for the confrontation between humankind and a global epidemic; the military language also pervades clinical and common references to the disease. AIDS is characterized as the result of the action of an insidious virus, HIV, that invades and attacks the human body. HIV disables the

"defense mechanism," the immune system, by destroying its core elements, the messenger lymphocytes. Sentinels defeated, the body is left without protection against the "enemies" that in normal circumstances would be armless and easy to defeat. The disarmed body whose T-cells have been destroyed by HIV is now exposed to bouts of pneumonia, toxoplasmosis, rare cancers, animal infections, tuberculosis. Devastated by hordes of those microbes, the body ages, shrinks, wrinkles, agonizes, and shuts off.

AIDS therapies are designed as chemical counterweapons in the biological micro-war. Most noble of all, antivirals are designed to kill and annihilate the virus that is the source of all evil, HIV. Since the virus is not really a living creature, but a simple and fully characterized chemical chain of abstract information whose segments have inanimate names like ENV, POL, or GAG, the anti-retrovirals do not really "kill." They are supposed to disable the process of "inverse replication" from RNA to DNA by targeting its central element, the enzyme **reverse transcriptase**.¹¹⁸ That is the action supposedly taken by

¹¹⁸New antiviral technologies have recently developed other targets in the process of viral replication. In 1995, there were a number of trials experimenting **protease** inhibitors, a type of drug that raised hopes among people with AIDS and that generated activist discussions and interventions. In early 1996, the first results of such trials were made public as quite promising -- and yet the drugs will be even more expensive than the first generation of anti-HIV drugs.

drugs like AZT, ddI, ddC, 3TC, the so-called nucleoside analogues, in the organism of people infected by HIV. The way these high-technology drugs perform their tasks, however, does not evoke the technical "elegance" of the "surgical weapons" used in the Gulf war. Destroying blindly around their target, they are better compared to the clumsy medieval canon balls. Targeting in the dark, they eventually destroy healthy non-targets, as well as they may also destroy other "enemies," the secondary infections associated with AIDS.

The impact of these "weapons" and strategies on the health of people with AIDS is a matter of debate. Most clinicians argue that administering antivirals improves the quality of life of the patient and retards the onset of symptoms and opportunistic infections, although it does not seem to prolong their lives. So far, antivirals do not cure. They do not disarm HIV, reverse the illnesses, or restore the body to what it was before. In the absence of better alternatives, however, most PWAs and their physicians prefer to take AZT at their own risk.¹¹⁹ After all, these drugs are the prime products of high-tech biomedical research. Even poorly endowed medical services

¹¹⁹An illustration is the resident physician who punctured his finger with the blood of a terminal patient in Rio, 1991; he chose to take AZT immediately, even though nobody knew whether it had any effect at that stage of possible early infection or if he was infected at all.

such as some of those I observed in Brazil prefer to allocate some of their limited resources to the purchase of antivirals rather than depriving their patients of that possibility. People with AIDS in Brazil went out of their way to raise money for a bottle of AZT,¹²⁰ and activists included the demand for its free distribution in their political agendas.¹²¹ Only those whose beliefs were based on radically different models (see chapter 2) chose not to take it. They claimed that its illusory effects were due to its powerful toxicity, which destroyed the infectious agents of the opportunistic infections.

The therapeutic weaponry for AIDS included a few extra anti-microbe devices: antivirals like foscavir (known as foscarnet) and gancyclovir (known as cytoven), directed against CMV (cytomegalovirus), acyclovir (known as zovirax) against Herpes, as well as antibiotics for regular

¹²⁰During the time of my research in Rio, AZT was extremely expensive, and difficult to fit into the budget even of middle class professionals (e.g. Daniel 1991a, 1991b). Some people raised money among family and friends to purchase the costly bottles of **Retrovir**. When somebody died, his or her medicines were distributed among the needy through informal or NGO-based networks. Even the much-criticized office of Eduardo Côrtes in the AIDS division (1990-91) gave priority to the purchase of AZT for free distribution, against a government that did not give much attention to AIDS or want to spend money with patients whose cause was considered lost.

¹²¹AZT actually launched the earliest steps of treatment activism in Brazil. Júlio Gaspar (1992) reports the discussions in GAP-SP as the motive for developing some broader reflection, which materialized with **Cadernos Pela VIDDA** (see chapter 4).

bacterial infections and antimycotics for the many fungal infections that grow in the context of AIDS. One by one, those "weapons" had been the focus of fights over their approval, release, trials, and price (see chapter 2).

As illustrated in Chapter 5, infectious disease regained prominence in biomedicine in the context of AIDS. To handle its multiple infections, and win the several "battles" against each of them, became the psychological and professional reward of clinicians who could no longer **cure** their patients as they had been accustomed to cure those with other infections. "Winning smaller battles within a broader war" was a common metaphor used by DIP doctors treating people with AIDS and their multiple infections (see chapter 5).

The warfare imagery in medicine (see Bader and Dorozynsky 1993, Jaret 1986, Latour 1984) pre-dated AIDS by many decades, owing its symbolic strength to Pasteurian **bacteriology**, which I will loosely refer as **germ-theory**. The idea that germs were microscopic enemies whose goal and **raison d'être** was to destroy the lives of humans and animals implied that larger organisms should have their defense and warfare devices. The view of the immune system as the body's internal **defense army** is therefore a

surrogate product of the demonization of microbes in the context of bacteriology. The success and medical accomplishments enabled by bacteriology helped strengthen military metaphors, and warfare became the dominant paradigm for disease and medical intervention.

Since the late nineteenth century, the understanding of disease in terms of the action of microbes had brought an extraordinary amount of activity for biomedical scientists, a number of research glories, and major medical and social accomplishments (see Kruif 1926). The new approach helped to control plagues, to differentiate and characterize particular diseases, to develop specific drugs and therapies, to reduce human suffering and surgery-related infections, and to sanitize cities, open frontiers, and improve public health.

Germ theory has also liberated humans from the self-blaming models of Galenic medicine and the terror of contagious miasmas. Disease ceased to be about morals, but rather about external agents; action was no longer about praying or being pure, but about knowing enough, and chasing out the evil microbes that invade our bodies. Morals and behavior become irrelevant in comparison to hygiene, sanitation, and antibiotics.

By reducing the scope of causality to the action of microscopic beings, germ-theory has also prevented the understanding of the social components of disease

determination. Ironically, it is the human disease whose "germ" is associated with Koch,¹²² tuberculosis, that best illustrates the limitations of the biomedical paradigm in the understanding of the prevalence of the disease. To this day, tuberculosis remains endemic in correlation with poverty and other **social** variables. The presence of the **mycobacterium**, or Koch bacillus, **per se**, does not determine the occurrence of disease.

The elusive search for a microbial cause for cancer in the 1970s was also framed by the germ theory paradigm. If scientists could identify an infectious agent for cancer, they could also develop adequate treatments and make this disease curable like many others (see chapter 1). They did not find a cause for cancer in the 1970s, but, largely based on the findings for cancer, they identified a cause for AIDS in the 1980s, and named it HIV.

Yet, as seen in chapter 2, **war** was not the only nor the best way to arrive at meaningful results regarding AIDS. Author Bruce Nussbaum build is argument in favor of community trials and the inventiveness of the PWA movement by contrasting it to the "war against AIDS" promoted by the medical establishment, and being lost by the "generals in charge" (1990:332). Not the generals, but the people who did

¹²²The German bacteriologist Koch is historically and medically as important as Pasteur and, in fact, they were rivals at some point, exacerbating German and French nationalism.

not invent the army, created the response to AIDS that seems to have worked the best. It was not the classic eradication, nor heavy-handed public health quarantine or **cordón sanitaire**. It was somehow a subversion of the very terms of the military fight against the invader virus. By establishing the possibility of living with AIDS and with HIV (see chapter 2), some PWAs unknowingly advanced the terms of a new paradigm. By creating the PWA identity, they challenged the expectation of their death with the very fact of their continuing to live, preventing further infections, balancing nutrition, lobbying the biomedical agencies for more research and better medication, and turning HIV infection into a chronic condition. In newsletters and activist networks, in a subculture of expertise in handling infections and immunity that dialogues and overlaps with biomedical expertise, they expanded the possibilities of coexistence with a virus that resists the contemporary medical war techniques.

Before the onset of AIDS, Susan Sontag's reflections on the use of metaphor for cancer and tuberculosis became an influential best-seller (Sontag 1979), and a line of thought that would be expanded and empirically substantiated in the field of AIDS (Crimp 1987, Haraway

1989, Martin 1990, 1994, Patton 1985, 1990, Sontag 1989, Threichler 1987, 1988, 1989, 1992). These authors emphasize the hyperstigmatizing effect of metaphors in illness: once depicted as a battlefield, the body itself becomes the illness, the sick person becomes the disease, risk groups become the danger, and affected nations become the enemy. An overload of meaning feeds back discomfort, disorder, and more suffering. Sontag pleads for a liberation from metaphors in disease and medicine. But how are we to replace the deeply ingrained germ theory that has framed our understanding of disease for a century, in which we achieved so much in the field of health?

A change of framework would be equivalent to a small scientific revolution, in the terms given by Thomas Kuhn (1962), that is, a paradigm-shift in the biomedical sciences. What could replace the solidly established military metaphors of germ theory? In the contemporary context of medical sciences, where current challenges include AIDS and a number of auto-immune disorders, we might think that significant changes should occur in the area of immunology. Since AIDS is primarily defined as a immune-system disease and has mobilized major research efforts and a concentration of funding, we might expect that major advances in immunology may happen in AIDS research. Acknowledging the vibrant character of that discipline, anthropologist Emily Martin (1994) asks whether

that vitality is related to attention to AIDS or whether it existed independently.

Having asked a similar question at the beginning of my project, my research brought me to a yet different conclusion. Even though AIDS has shaken the field of immunology, it does not seem to have caused a major conceptual transformation. Frameworks remain the same in the busy and anxious field of AIDS research. Even though some people involved with AIDS have come up with different concepts and models, including the challenge to the warfare paradigm, no central change has (yet) taken place. It seems as though the majority of those involved with AIDS have been too busy saving lives or pursuing their careers to spare the time to consider a radical look beyond the main framework.

It was **not** within the field of AIDS, but right by its side, within the realm of basic science research, that I found the most radical questioning of the war paradigm. I heard this statement from an immunologist:

There is a **dogma** about anything in immunology being of **defense**... like **military**... reinforced by the old textbooks of immunology... where, for instance, lymphocytes are [represented as] little soldiers.... Doctors are trained under a paradigm where they are the good ones and the bugs are the evil ones... doctors must control a therapeutic weaponry, know it well and handle it well in order to kill the bugs... (Santos, interview)

This seems like the insight of a radical literary critic engaged in the deconstruction of scientific

discourse, but it could not be further removed from that. It is actually an extract from an interview with two immunologists in one of the most prestigious research centers of South America, Instituto Oswaldo Cruz, Rio de Janeiro. My interviewees elaborated further on the inadequacy of military metaphors in medicine, infectious disease, and immunology:

From a conceptual perspective... [the war between good doctors and their drugs against evil bugs] is an **absurd**. What you have is a disadvantageous competition between transnational corporations, producing new drugs, and the microorganism, producing new resistances, which leads to nowhere except to cash profit for the corporations. It's **absurd**. You forget about health, about the healthy carrier, life in coexistence with bugs... (Santos, interview)

If I was looking for a different paradigm, there were some clues to it. Their reference was something other than the model of antagonistic war, which they described as "absurd." Instead of demonizing the bugs and talk warfare, like the lay, mediatic version of immunology (Jaret 1986), the immunologists I interviewed argued for a broader understanding of the immune system as **complex system of interacting networks** among which there was the ability to differentiate self and non-self. This view is shared by a number of other immunologists whom I either met or heard about, including some of those interviewed by Emily Martin at the Johns Hopkins Medical School (Martin 1994). In her anthropological exploration of concepts of immunity from

high ranked research laboratories to the streets of Baltimore and the mainstream media, Martin concluded that even though many immunologists think that warfare accurately portrays the functioning of the immune system, there is no consensus among scientists. The concept might better be described as a media favorite, one that does not even reverberate into the far more diverse common street opinion.

Immunology is a dynamic field in which several competing models co-exist. The "organism-centered," or network approach (Coutinho et al. 1984, Varela 1979, 1988, Varela and Coutinho 1991, Varela et al. 1988, Vaz and Varela 1978) has been expressed in mainstream publications like **Immunology Today** and **Immunological Reviews**, but is not, so far, mainstream theory (Martin 1994:110). Due to the overwhelming presence of molecular genetics in contemporary biology, complex system frameworks are more or less suffocated, as Brazilian immunologist Nelson Vaz emphasizes (1992, personal communication). They are not as popular as the over-specialized "molecularized" thinking that is associated with the use of expensive high technology and gets most of the spotlight and funding. Far from the molecularized mainstream, "network" immunologists trace their understanding of self-regulatory systems to Metchnikoff and the origins of immunology, and often refer to the Australian immunologist MacFarlane Burnett (Tauber 1994, Vaz and Faria 1992; see also Kamminga 1994).

In their view, bugs and microbes should not be automatically taken as "bad" and "enemies." One of the scientists I interviewed referred to a friend's project of writing "the history of pathology from the perspective of the microorganisms." Microbes do not have the teleological **purpose** of killing, assaulting, invading and destroying the larger organisms, nor are they evil except in our human interpretation. Illness is just a particular case of interaction between microbes and hosts, and the immune system does not exist just to act in those exceptional moments. Actually, immune responses may not derive just from the differentiation of self and non-self, which is the model more often presented as an alternative to the more militaristic one. Differences and contradictions exist within the self from the embryonic stage, as Metchnikoff showed almost a century ago. The immune-system builds up in response to the internal contradictions within the self from its very early stages (see Tauber 1994, Vaz and Faria 1992).

My interviewees pointed out that this inadequate and partial understanding of the relationship between the organism and the infectious agent lies at the basis of the persistence of war paradigms in contemporary medicine and immunology. That misunderstanding stems from the fact that most research has focused on the exceptional and high intensity phases of acute infection or transplant

rejection, with the correlate disregard for its function in non-acute states.

what is the immune system doing, when you are not rejecting a transplant, when you are not fighting an "evil" bacteria? What is it doing then, why does it exist at all? [The problem is that] there is too much emphasis on [the study of] exception. Illness is the exception, we spend most of our lives healthy, interacting with all those bacteria, viruses, dusts -- and we seem to manage quite well all these "aliens" (Pirmez, interview)

My "informants" had a powerful insight about social metaphors and, like critical social scientists, they found inappropriate and anthropocentric the current model of the immune system as a human army that stands still while waiting for attacks. Based on the social experience of wars and armies, that model does not account for much biological activity nor for the very existence of the immune system. This is not the only analyzed case of anthropocentrism in biology (e.g. Thomas 1974), and dominant cultural themes and views of warfare are used cross-culturally to represent biological processes, as it has been documented for the New Guinean Fore (see Lindenbaum 1979).

Unlike social scientists, whose analysis consists mostly in drawing correlations between the metaphors used in biomedicine and external social variables like gender, power, economic and belief systems, my "informants" had a sense of what to look instead of the perceived warfare. In their view, the immune system should not be studied by

focusing on the intense and exceptional activity that goes on in periods of acute infection. The banal and unexceptional trivia of everyday life, just like for early ethnographers, seemed the "revolutionary" key for the shift in understanding. Resisting to the study of the "special," another immunologist explained:

We are driven to study diseases... but my interest is about normal physiology...how the lymphocytes recognize the antigens, and how, in a general manner, they guarantee balance and health in the internal environment of the organism... (Reis, interview)

It is not only immunologists and biomedical researchers who fragment knowledge and pursue details while losing sight of the whole picture; detailed questions are easier to handle and hyper-specialization is cultivated in the contemporary technologically oriented scientific culture, even if they are far more expensive and exclude the less-endowed research centers from making contributions. In the case of immunology, the pursuit of specific diseases and details on the infectious agents matches the fragmented character of the production of knowledge, to the extent that hardly anyone has a good understanding of how the immune system works outside the "feisty" periods of response to the presence of external bacteria. Moreover, as many of my interviewees in AIDS clinical settings imagined, research in basic immunology

would be even more complex and expensive than the already expensive approach to the molecular structure of the virus.

The "network" approach, which is understood in terms of complex systems and chaos theory (see Tauber 1994) and stems from Metchnikoff's theory of primal internal contradictions, is an attempt to draw a comprehensive picture of the immune system. Even though the model seems too complex to be adopted in clinical situations, its implications for treatment may be surprisingly simple. Overcoming the molecularization trend and the theme of specificity, "magic-bullets" give way to generic therapies that can be as elementary and inexpensive as the oral ingestion of foods.¹²³

The critique of the warfare metaphor in immunology from within an immunology laboratory was a novelty to me. I

¹²³In the 1994 AAA conference in Atlanta, anthropologist Emily Martin furnished a number of examples of current trends for immune system diseases like multiple sclerosis and arthritis, which included the ingestion of bone components generally left out of the human diet. That type of data confirms what the immunologist Nelson Vaz claimed to be the reason for his epistemological rupture with classical immunology, the long documented and observed phenomenon of oral immunization by the ingestion of plants by certain animals. Vaz (1992, personal communication) overcame that epistemological crisis by adopting an epistemology of dynamic systems as expressed by philosopher of immunology Francisco Varela (1979).

thought, as my experience with busy clinicians seemed to confirm, that scientists were not supposed to open their own black-boxes. They might think and speculate beyond germ theory, but since the advent of bacteriology they had framed their action as if they were pursuing the "villain" bugs which caused the diseases. Their world-view included identifiable, characterized diseases, for each disease a microbe, and for each microbe a drug or set of drugs. The increasing interest on genetics and on the genetic co-determination of many diseases did not dismiss the overwhelming power of the germ theory, especially among infectious disease specialists.

Associated with the findings of Pasteur, most accounts of bacteriology's social history emphasize the impact of sterilization rules and their benefits to medical care and human health. Here we will follow another account, one that is very close to the history of Brazil and sheds a different light on the symbolic associations of germ-theory: **Tropical Medicine**. Its most celebrated period corresponds to the "conquest" of tropical disease, when the "warfare" style merged with the imagery of frontier breaking which fits so well the mythology of scientific discovery.

Tropical diseases were seen as a fate of geography for vast regions of the globe, many of which were European colonies from the sixteenth to the nineteenth century. A

former colony that became independent in 1822, Brazil shared that stigma and burden. The possibility of **progress**, the positivist motto adopted by the Brazilian Republic in 1889 and printed in the federation flag, was jeopardized by "tropical scourges." The internal frontier could not be developed and settled; its populations suffered heavily from a number of mostly unidentified pestilences. The urban poor, equally, dwelled among plague and yellow fever. Fears of contamination scared European migrants and prevented them from coming to the country, and had a negative impact on international trade. In this context, and in spite of all the resistance of the public agencies to supporting science, bacteriology became a central historical element of national development; in retrospect, it is represented not just as a scientific theory, but also as a liberating paradigm, a doctrine, and a kind of lay religion that was to save Brazil from backwardness and allow for progress. The ports and cities and their pests on the one hand, the inland frontier and its disenfranchised inhabitants on the other, both had to be rescued from the ills that prevented progress; a difficult goal in a vast society that was just out of slavery and had a highly stratified society with considerable socio-economic inequities.

The conquest of infectious disease is remembered as one of the central sagas in Brazilian history. The doctors that helped fight off the endemic plagues are represented

as civilizing heroes, their portraits hanging in the walls of many research laboratories. They are part of a national iconography that transcends local history and represents the entry into the modern world, a process that at some levels continues to the present day.

The most celebrated of those pioneers is Oswaldo Cruz, after whom the leading South American research institute is named, in Rio de Janeiro. Historians describe him as quite isolated in his early devotion to the new and revolutionary bacteriological theories, a drive that in 1896 led him to sail for Paris in order to specialize in microbiology at the Pasteur Institute. There he met Metchnikoff, the author of the theory of fagocytose and a founder of immunology, who became a close friend and invited him to work in Europe. Oswaldo Cruz preferred to return to Rio, which he did in 1899, and "use there what he had learned in France" (Moreira 1974:39). He was able to put it into practice right away, for bubonic plague had appeared in several of the Brazilian harbors. First appointed to the Board of Hygiene, and later head of the General Public Health Department, in 1903, Cruz soon became involved with the historic campaigns against yellow fever.

Local beliefs about yellow fever were based on "miasma" theory. People believed that the simple proximity of the sick and their clothes caused contagion. Scientists had been prone to believe that some type of micro-organism,

"bacillus icteroides" or "cryptococcus xantofagus", could be responsible for the disease, but nothing could be proved. When a North American expedition visited Brazil for research on yellow fever in the late 1880s, the disease was dormant and they found nothing. However, by the time Cruz returned to Brazil there was some evidence from Cuba that yellow fever was indeed caused by a microorganism. The Cuban doctor Carlos Finley (considered by Cuban historians the discoverer of the cause for yellow fever) had traced the transmission of yellow fever to mosquitoes; the U.S. mission led by Walter Reed (considered by American historians as the discoverer of the cause for yellow fever) conducted further experiments which at the same time dismissed the hypothesis and confirmed it by introducing the supplementary concepts of an **incubation period** and a **transmission cycle** (see Delaporte 1991, Moreira 1974). Inspired by the Cuban findings, and right before Walter Reed addressed the Pan-American congress, the **Paulista** doctor Emílio Ribas published an article in January 1901 on "the mosquito considered as an agent for the propagation of yellow fever" (quoted by Moreira 1974:73) and coordinated the first Brazilian campaign against mosquitoes in Sorocaba, São Paulo.

The campaigns against yellow fever in Rio had to mobilize information and propaganda in order to change people's beliefs and attitudes. Instead of burning the

clothes of the infected, people were urged to protect themselves from mosquitoes and prevent them from breeding. Emílio Ribas tossed himself in the bed sheets of a yellow fever patient to show the public that there was no risk of contagion by clothing, and that the danger was in mosquitoes. Oswaldo Cruz was ridiculed in the media for the absurdity of chasing insects, and caricatured in duels against giant mosquitoes (Falcão 1973). The success of the campaigns¹²⁴ strengthened Cruz' political power, but not enough to guarantee the approval of a bill making official the conversion of the serological institute of **Manguinhos**, where vaccine **sera** were produced, into a center of experimental medicine. The oligarchies considered it a waste of money, merchants opposed the state-supported manufacture of medicines, and the medical college opposed the teaching of medicine outside their own walls.

Only after Oswaldo Cruz won an international award in 1907, at the Hygiene and Demography Exhibition in Germany, and become a national hero, was the Institute of Manguinhos officially recognized. It was endowed as a research center and named **Instituto Oswaldo Cruz** in 1908. By that time, its

¹²⁴Besides yellow fever, Cruz led a campaign against the bubonic plague that included the extermination of city rats, and a campaign against smallpox, using vaccine serum produced in the institute. The later generated the insurrections known as **revolta da vacina** (vaccine revolt), a mass response against the harsh policies of public health officers (see Carvalho 1987). 1

director had also built the exquisite Moorish castle that lodged the serological institute for many years and that to this day stands out on the campus. Sparing no expenses and luxuries in the architectural details and finishings, Cruz is said to have wanted the castle to stand out over the **mangue**, the swamp above which it was located, "just as science stands out and shines over the ailments of the masses" (see Benchimol 1990). Yet another military evocation.

With the structure of a research center, **Manguinhos** surpassed the **Butantan** Serological Institute of São Paulo, whose coordinator Adolpho Lutz later joined the carioca team. The campus of Manguinhos was the site for most pioneering research on infectious disease in Brazil, always articulated with major European and North American research centers.¹²⁵

From Manguinhos also came the coordination of the scientific campaigns into the hinterland. Those expeditions, again, were consonant with the dominant paradigm of germ warfare. Their mission was to conquer, civilize, and annihilate the microscopic enemies. By medicalizing their ills, they also helped to remove the stigma of laziness formerly attributed to the inhabitants

¹²⁵Manguinhos was also a must for celebrity visitors; house documents include photographs of visits by Albert Einstein and major scientists as well as royalties and politicians from different countries.

of the tropics. Bugs, not climate or race, should be blamed for their ills. The imagery of those expeditions portrays young scientists (always white, male, and often from the urban elite) traveling in the wild hinterland among the afflicted population (poor, creole, any age or gender) who exhibited a number of scourges (see Thielen et al. 1991). The scientists are represented as combination of traits from miraculous saints bringing relief to the ailing masses, civilizing heroes bringing redemption with their medical paraphernalia, victorious warriors defeating the enemy, and triumphal hunters chasing microbes.

The campaigns covered the hinterland of Minas Gerais, Mato Grosso, and the Amazon. One of the most celebrated findings was the identification, in 1909, of the American trypanosomiasis, thereafter named **Chagas disease** to honor Carlos Chagas. This same scientist is credited with all the discoveries related to the disease: he identified it among a mass of ailments, discovered its infectious agent, its vector of transmission, and its cycle of infection. Brazilian medical history celebrates not one discovery, but the simultaneity of **four discoveries**, all by the same scientist: the identification of the vector, the infectious agent, the animal reservoirs, and a human case characterization (see Chagas 1990:84). Also within that context comes a discovery that would prove later to be of major relevance: the protozoa initially named

schizotrypanum, initially described in 1909 by Carlos Chagas as a possible variant of *trypanosoma cruci* that affected the lung, and later described by Delanoe in 1912 as ***Pneumocystis carinii*** (Chagas 1990:85).¹²⁶

During the construction of the railroad in the inland state of Minas Gerais, Chagas was called in to implement malaria prevention. He set up his headquarters in Lassange (Benchimol 1990, Moreira 1974:157). Reasoning by analogy to his knowledge of malaria (see Stepan 1976:120), the researcher paid attention to the hemophile insect ***triatoma infestans***, which was quite widespread in the uncoated walls of poor rural houses. Locally known as **barbeiro** ("barber"), because it sucked blood from the human face, the insect might, as different mosquitoes were for malaria and for yellow fever, be the carrier (vector) for a microorganism that could be causing the swollen necks, sweats and malaria-like symptoms that were later, together with heart disease, characterized among the Chagas ailments.¹²⁷ He

¹²⁶p. *Carinii* remained described as a protozoa within the context of the AIDS epidemic, and often referred as a rare disease that affected infants and elderly. Only some years into the AIDS epidemic, with the correlate exceptional pace of biomedical research was *P. carinii* reclassified as a fungus.

¹²⁷The later characterization of Chagas disease is far more complex, as a slow-progressing disease that involves cardiac pathologies. One of the most interesting recent findings in Chagas disease was the understanding that damage in the context of Chagas is also caused by the lymphocytes of the person infected, in a type of auto-immune response to "disguised" lymphocytes, rather than by

isolated a trypanosoma different from the one that causes sleeping sickness in Africa, and named it **trypanosoma cruzi**, in honor of Oswaldo Cruz. The **barbeiro** became the target for disinfestation and fumigation with DDT in order to prevent transmission, and treatments for the sick were developed in the meantime.¹²⁸

Polemics around the authenticity of this disease as a new and separate one, as well as about the causative role of the newly identified agent, persisted throughout the 1920s in a way that is reminiscent of today's fringe discussions about AIDS. Polemics challenged the veracity of the newly defined disease (see Chagas 1990:187-230). Only after other Latin American countries expressed their interest in the study of American trypanosomiasis was its study re-implemented in Brazil (Chagas 1990:187).

The field consolidated and has attracted many researchers up to the present day. Protozoology developed significantly in Manguinhos due to the study of Chagas disease (Benchimol 1990), and several lines of research were implemented around it. The original research on the molecular interaction between the insect vector and the microorganisms that had the **barbeiro** and the **trypanosoma** as

the direct action of the infectious agent (Ribeiro dos Santos, 1992, personal communication).

¹²⁸For a detailed account of the multiple aspects of Chagas disease, see Briceño-Léon (1990, 1993).

a model served to explore basic immunological questions that can be extrapolated for other infectious diseases with insect vectors, and that can also have direct applied effects. For instance, one group of IOC researchers found out that certain wild plants block the infectiousness of the trypanosoma in the barbeiro carrier, a finding that may have important consequences in the prevention of **Chagas** disease transmission (Garcia, 1992, personal communication).

It is interesting that the first time I heard a consistent development of a radical critique of the germ-theory paradigm it came from within the tradition which had been inspired by the toughest anti-microbe wars. Interesting, but not surprising, for the field has remained a vibrant and fertile area of research. This particular finding matches the suggestion, by historian of Brazilian science Nancy Stepan, that "a concentration on Brazilian problems did not rule out the possibility of making discoveries on disease mechanisms in general" (1976:122). The vitality and universal value of biomedical research in the context of Brazilian tropical medicine has been documented by the historians of **Casa Oswaldo Cruz** (e.g. Benchimol 1990, Benchimol and Teixeira 1993, Britto 1995,

Thielen et al. 1991). The work of this group, a history and social science research unit within the larger FIOCRUZ, is itself a sign of the social interface of the local medical field. The strict, unicausal theories of bacteriology gave way to a complex field of thinking that accounts for the host-parasite interaction in the determination of disease and for the social variables involved.

Another important site of knowledge production in the interfaces of the biomedical field is the National School of Public Health (ENSP), also part of FIOCRUZ. It has produced works that combine social analysis and biomedical knowledge, and has created a tradition of a critical, creative atmosphere that constantly produces new knowledge on medical problems. A number of works conducted by local researchers explore the convergence of social and biological variables in the prevalence of infectious diseases.

Malaria, for instance, has been shown in correlation with the type of deforestation practiced in the Amazon. The disease, biologically caused by the *plasmodium falciparum* and other variants of a mosquito-transmitted microbe, affects diversely the different social strata. The first series of small-holding settlers generally succumbs to the disease; the second wave sells the land at the first sign of malaria, and by the time the land is suit to be settled

it is already concentrated in big estates.¹²⁹ Equally, the prevalence of schistosomiasis is directly correlated with land-tenure variables. Tuberculosis, dysentery and child mortality continue to be directly correlated with poverty and undernourishment. Leptospirosis prevails in the city slums where open sewers carry infected rat's urine, an effect of the chaotic urban growth and the reproduction of poverty in the cities. Chagas becomes an urban disease through the transfusion of infected blood. Leishmania, dormant for years and considered a disease of the wild spaces, reappears in the perimeter surrounding households, both in urban slums and in the countryside. Cholera, which had spared Latin America for centuries, has been re-introduced to the continent via trade in the Pacific Ocean. It decimates the people from the Andean countries, and threatens the inland population of Brazil.¹³⁰ The

¹²⁹Insights on the social determination of malaria as well as other "tropical diseases" were provided by Dr. Maurício Peres, from the Nucleus of Studies in Collective Health, UFRJ, Dr. Paulo Chagastelles Sabroza, from the National School of Public Health, FIOCRUZ, and Dr. Celso Ramos Filho, from the University Hospital, UFRJ, as well as by a number of conferences attended during my research. Errors or misjudgements in my presentation of the issue of my own responsibility.

¹³⁰Actually, cholera may be taken as an example of the rapid response of socially oriented biomedical research institutions like FIOCRUZ. The South American cholera epidemic started during my fieldwork in Rio, and was the topic of much speculation by the media and even the government. Estimated numbers of cholera cases in Brazil, if no action was taken, reached the hundreds of thousands. The Minister of Health, Alceni Guerra, used the opportunity to create a quite original campaign involving bare-foot educators in the countryside, but this was no more than a

overwhelming evidence of the social determinants of disease distribution make its understanding a component of local medical culture. Rather than a question left for social scientists or public health niches, it is a part of medical knowledge, and moreso of the infectious disease specialty.

Local researchers have also pursued a number of exciting exploratory projects in microbiology. Studying the biology of "tropical" diseases, they have been able to address fundamental questions in biomedicine that have been left off the "molecular genetics bandwagon" (Fujimura 1988, Vaz, 1992, pers. com.) or "molecularized imperialism" that dominated most research programs in the last decade.

As infectious diseases remain a major public health problem, and are also acknowledged as a social and development problem, the original alliance between pioneer researchers and the ailing masses remains. Attracted either by pure research reasons, by social causes, by the specificity of the field, by its national tone, or by other

pretext for a corrupt massive purchase of unnecessary goods like bicycles and umbrellas. He was dismissed as a consequence of that overpriced purchase from his political friends who owned a store in the city of Curitiba, Paraná. Independently, a team of FIOCRUZ that had been involved in cholera research went to the Peru-Brazil border and evaluated the situation for immediate action. They understood that the feces-ingestion circuit, responsible for the propagation of **Vibrio cholera**, was different in the Brazilian and the Andean sides of the border; in Brazil, a more widespread sanitation helped prevent catastrophic spread of the epidemic, and instead of 200,000 cases only 20,000 were recorded.

reasons, a number of qualified researchers were constantly drawn into the field of infectious diseases in Brazil. The local concentration is exceptional, and, dialoguing with other research centers and some international networks, contemporary Brazilian scientists have been able to pursue aspects of infectious disease and immune functions that may pass unexplored in the high-technology driven centers of Europe and North America,¹³¹ where the field of infectious disease had declined significantly (see Garrett 1992) and molecular biology has had hegemony in biological research and thinking.

In FIOCRUZ, in UFRJ, in other research institutions in Rio or São Paulo and other Brazilian cities, exciting research took place in medicine, in the social sciences, and the interfaces of medical and social questions. But let us not be trapped in a "nationalist" take nor in the manicheist dualism that both modernization and dependency theories have framed. It is not an essentialized "third

¹³¹In these countries, the less vibrant field of infectious diseases has been left mostly to military medicine or former colonial institutes; the field of immunology before AIDS was largely associated with the transplant industry or low-key allergies, and promising careers were pursued elsewhere, like the molecular biology of cancer or genetic mapping.

world knowledge," or a "Brazilian science," that emerges here. It is knowledge produced under the particular circumstances I have attempted to describe; an idiosyncratic combination of extra-developed, cosmopolitan sectors with underdeveloped contexts. A strict definition of a "third world" sphere of thinking and science-making would lead us into the conceptual traps that have haunted efforts to dismiss scientific knowledge as bourgeois, male-chauvinist, or western-imperialist. If essentialized, the privileges of the "partial perspective" (see Haraway 1988) can turn into parochialism and the resulting alternative, may become narrower instead of more comprehensive.

Most of my interviewees in clinical and biomedical research settings had a clear understanding of the dilemmas of being engaged pioneering, top level research problems while they were surrounded by the afflictions of underdevelopment. That structural tension appeared at all levels, from the allocation of budgets to the allocation of personal time, and from the choice of research problems to the choice of a sphere of action. Colorful descriptions of the structural tension abounded: high tech laboratories whose filters had broken because the children from the slum next door used the water reservoir to swim and play; a

research facility equipped to use PCR¹³² in a city that cannot perform a simple necropsy to assess a cause of death;¹³³ the pursuit of theoretical research questions in a context where even the existing knowledge cannot be applied to save lives because there are not enough material conditions; the purchase of expensive antivirals when simple antibiotics are missing; the special focus on AIDS when there are more people dying of tuberculosis, malaria, and malnutrition; the use of satellite conferences for updated research discussions when most people cannot even read.

This scenario is less a composite of world types than the face of how contemporary world is: not the traditional geographic partition of developed and underdeveloped, or, as during European colonization, of metropolises and satellites, but a constant recreation of centers and peripheries, flexible and mobile centers, modern-generated peripheries, all next door to one another.

¹³²**Polymerase Chain Reaction**, a biochemical device for detecting aminoacid sequences that make it possible to check whether a specific virus is present or not. PCR became popularized in HIV research; unlike the antibody-based tests like ELISA and Western Blot, PCR verifies if the actual virus (not the immune responses to it) is present.

¹³³This was a real case witnessed in the city of Salvador in Bahia, in 1991. Dr. Bernardo Galvão-Castro, who moved from FIOCRUZ in Rio to organize a special and well-equipped research laboratory in Bahia, shared with me the contradictions and distresses experienced by researchers in such fringe situations.

In some cases, as I could observe in Brazil, that proximity had been incorporated in the production of knowledge, and became central to the local production of biomedical science as well as clinical practice. It is no coincidence that social epidemiology, social medicine, and the important field of infectious disease flourished in Brazil in close relationship to the classical endemic and epidemic diseases. The problems locally defined for research priorities are closer to being universal, global human problems than are those that may be defined in technology-oriented research settings.

It might seem, therefore, that AIDS had an ideal site for the local approach to science to make its contribution to global efforts. It seemed so, at the time when apparently genuine global efforts from international agencies and different partners conducted the international responses to the epidemic. However, and for the reasons I have pointed out throughout the text, AIDS research rapidly became a technology-oriented field, which implies a kind of research more dependent on first world type of resources, strategies and questions. "AIDS became like another cancer," remarked one of my interviewees, meaning that research became technology-dependent, adopting the strict models of biomedicine. "Only if the epidemic gets out of control, and does not get a vaccine or any classical treatment, might our [social] knowledge matter," said the

same social epidemiologist, seasoned in the understanding of the broader social determination of disease.

Expressed in high technology language and protocols, and surrounded by a kind of emotional investment, anxiety, and exceptional funding, AIDS research rapidly absorbed into the high-tech style of medical research all the different efforts to approach it. One physician commented

even the diagnosis of tuberculosis has now to be performed in the high tech patterns defined in the first world, with expensive tests, when we always performed it based on clinical and differential diagnosis at no extra costs... it seems wrong... we should be engaged in the development of more affordable means of diagnosis, that could be valid anywhere (João, 35)

Some researchers mocked the high-tech style as shortsightedness:

You know, sometimes [North] Americans demand the exact terms of proof they defined, otherwise they will not accept your data. If I send them the corpse, the end of it, with the picture of the corpse, it is obvious that it cannot be anything else than a corpse, and they will ask for this and this and that assay in order to prove that it is really the corpse, that it has the smell of the corpse, that it is chemically proven that it is the corpse... (Rodrigo, 50)

Other times, they saw it as a perversion of the system, fueled by the profit-making mentality of the corporations that produce technology:

who wants to see a simple-technology substance that could sterilize the blood in blood banks, for safe blood transfusion? Can you imagine the amount of

money in serological test kits that would not be made by the manufacturers? (Rodrigo, 50)

While despised by some of my interviewees, the "high-tech mentality" was pursued by many others who concentrated their efforts on equipping laboratories with competitive testing and assessment devices. Researchers involved with AIDS, whether they were aware of it or not, may not have had any other choice but to adopt the idiom of high technology. This was the language in which all the new medical knowledge was expressed, and the only one through which their efforts could be accounted for. That same reason made them place themselves in a structurally subordinate position: they will never have the amount of reagents, or laboratory facilities, equipment, lab staff, libraries, communication equipment, and money necessary to produce the level of competitive research that is acknowledged by mainstream medical publications.

we should limit ourselves to research here things that they (first world) will not research there, or have no interest in there. The type of things that will not lead to a Nobel, but can add to knowledge on AIDS, and that we can produce here safely.
(André, 37)

Some interviewees had a clear idea that the research funds allocated by international agencies to Brazil covered only clinical descriptions, epidemiology, and eventually the social aspects, and the local characterization of viral varieties, but no major influential basic research. Some

acquiesced with that order of things, which found powerful support in the technological argument: how could Brazil compete otherwise? There is no money, no resources, no infra-structure.

Another group among my interviewees in basic science despised that type of conformity. They insisted that scientific creativity has nothing to do with the amount of high technology, and that the most needed resource -- the patient with the infections -- was fairly abundant in Brazil, certainly more than in the northern countries. Mystification by high technology separated the waters between the two types of researchers. And, as far as I could observe, research on AIDS was absorbed by the more technology-oriented style, in Brazil as elsewhere. As a consequence, the "original" contribution that the local thinking and style of research had developed around Chagas and other "tropical diseases" was not incorporated into the "global" efforts to respond to AIDS.

However, the scientific creativity that heightens the possibility of a paradigm change in immunology or in the social determinants of diseases is there, alive and well, productive and vital, side by side with AIDS research, and it may be ready to incorporate more comprehensive models in the general production of knowledge in the disease at a later date.

CONCLUSIONS

After approaching the field of knowledge about AIDS from several perspectives, it is time to evaluate how the ethnographic data and analysis address the questions raised in the first chapter concerning the social construction of scientific knowledge in the context of the contemporary world.

In the account of the AIDS social movement and treatment activism in the United States (chapter 2) I analyzed a process that we may now call **the unleashing of knowledge-making**. That process made transparent to the public what used to be the opaque walls of research or, to use a favorite metaphor of science analysts (e.g. Latour 1987, Pinch 1992), opened wide the "black boxes" of science. They were not deconstructed and torn apart by the usual academic critics, who, for this purpose, came relatively late. The force that broke into the "ivory towers" of science came from society itself, or, to be more precise, from a segment of society that had never been involved either with science or with its analysis: those who were directly affected by the disease.

With their lives at stake, AIDS activists scrutinized the reasons why they were not getting a cure in a century

whose claims to fame included medical victories against infectious disease. Initially they blamed government and scientists' lack of interest in their lives. Since most of those affected by AIDS were gay, activists pinpointed homophobia and prejudice as the underlying reasons for government inaction. Once scientists became motivated to conduct research on AIDS, and government money as well as private funds were raised, activists blamed other targets, like red tape and bureaucratic inertia, corporate greed, and the personal vanity of individual scientists motivated by grants, awards, and publications rather than by the prospect of improving public health and saving human lives. Equally fueled by anger and filled with indignation were some of the journalistic reports on AIDS. They depicted greedy scientists and businessmen conspiring behind closed doors about the profits and awards that AIDS might bring them, while disregarding the needs of those affected by the epidemic.

When the obstacles of bureaucracy were reduced by political decisions, and when scientists as well as laboratories became publicly accountable, activists realized that the problem was more profound, and that the lack of scientific imagination and experimental daring were as powerful limitations to the achievement of new knowledge as the will of scientists and governments.

Meanwhile, activists unleashed the process of knowledge-making in several directions. They developed

their own community research. They fought and negotiated with public agencies and with pharmaceutical corporations. They made recommendations and sat on advisory committees. They crossed the previously closed doors of scientific research. The process of science-making leaked to society. Knowledge started to be produced outside laboratories too. Negotiations between scientists and society defined the standards of consensus about critical "scientific" issues, like clinical trials and drug approval.

As social activists became co-producers of knowledge and shared the responsibilities of research and its results, their attitude towards the "black-boxes" of science moved from anger to disenchantment. As research doors opened, either as a result of forceful pushing from the outside or from negotiated agreement between the parties involved, and as the boundaries between outsiders and insiders became blurred in the process of negotiating the terms of action and defining research questions, depictions of greed gave place to disenchantment with the limits of current knowledge. This is where the subject begins for those who are engaged in the social study of scientific knowledge. Are those limitations and our understanding of them a sign that things are about to change, and that we may be in a period of Kuhnian revolutionary science?

From outside the scientific establishment, beyond the wider circle that involves those who protest at the agencies' doors and those who negotiate with them, some voices of radical dissent in the U.S. claimed that the basic assumptions of current knowledge about AIDS are wrong. Duesberg (1987, 1989, 1992, 1994) and followers dismissed the role of HIV; Root-Bernstein (1993) blamed the rapid and sloppy process of achieving consensus on AIDS; Coulter (1987) saw it as another form of syphilis; the **Spheric** (1994) called AIDS a "hoax"; the **New York Native** consistently dismissed the term "AIDS."

From one perspective, these views seem dangerously irresponsible: they challenge the very basis from which every single tool to act upon AIDS derives. If those are questioned, what else is left? Relativism is uncomfortable in matters of life-and-death; when health is at stake, most of us prefer to follow undeconstructed prescriptions. Seen from afar, though, those voices are merely demands for a change in knowledge models. They may be inadequately articulated, but they remind us that knowledge results from a constant process of construction and change, and that knowledge about AIDS is particularly fragile and volatile. Examples of certainties being replaced by their opposite or by very different ones abound, including in the various

subfields of AIDS knowledge, from etiology and pathogenesis to treatments, epidemiology, prevention, and social policies. What was thought to be a gay cancer became an infectious disease. What was related to modern decadence became associated with primal infections originated, like humankind itself, in equatorial Africa. What was seen as a disease of the urban metropolis and developed countries became a Third World burden, affecting the disenfranchised peoples from Africa, Asia, and Latin America. What was associated with anal sex became linked to pregnancy and birth. What was seen as an inevitable killer disease became in some cases a treatable chronic condition. What was seen as the only therapy, AZT, was discarded as almost ineffective. What was seen as environmental and life-style related was later attributed to a virus. What was seen as having only a viral etiology became recognized as having multiple factors.

What constitutes official and acceptable knowledge in AIDS changes constantly, mirroring the very nature of science making. Why do some ideas remain while others are rejected or revised? In the logic of scientists, ideas are replaced when there is either evidence against them or a new model that better explains the phenomenon in question. The acceptance of a new model is a matter of **consensus**, an unquestioned process for scientists and yet, from the social science perspective, it is the center of the

problem: what are the social variables implied in that process of legitimation?

With the data presented in chapter 2, it is possible to argue that the AIDS social movement in the U.S. introduced an innovation in the process of consensus-production. The same social actors that "opened" the doors of laboratories became part of the process. They influenced the criteria for clinical trials, trial design, drug approval, AIDS case definition, prevention strategies and, later on, research questions in basic science. What had been decided by networks and communities of thinking scientists in the past was now also discussed by those directly involved in the issue.

This fact challenges the late 1970s and 1980s wisdom of social constructionism and ethnographies of laboratory (e.g. Latour and Wolgar 1979, Latour 1987, Knorr-Cetina 1981). In the context of AIDS, scientific knowledge is not just what is produced within the laboratory doors, seeking for grants and peer recognition, measured by publications and acknowledged by awards. No longer exclusively composed by networks of peers driven by academic rules or subject to the pressure of profit-making corporations and state policies, the social basis for the negotiation of consensus was expanded to the community of people whose motivation was their own survival. Does this make the knowledge produced less "relative," or "arbitrary"? Although we can

describe the new knowledge produced as revolutionary and innovative, we cannot conclude that it is "truer" and more "absolute" than what was produced in the traditional form; we can only say, in a "quantitative" understanding of the word, that this knowledge is more "universal," or extended to more people. We may also have found an example for discussing the question of the social conditions of "scientific revolutions," a matter that Kuhn (1962) left to be pursued by others (Mulkay 1972).

My initial questions were not limited to the social construction of science, but extended to its relation to the contemporary moment in world history. Roughly at the same time as activists in the United States started the process of unleashing science-making, international agencies like WHO envisioned the global dimensions of AIDS and pushed forward an agenda of global action. Did that "global" effort correspond to a search for universality? Would it have an impact on the production of knowledge and make it even more "universal"? Was there a possibility of a generalized "global unleashing" of knowledge making? Such a scenario raised further questions about the plurality and multivocal nature of contemporary culture and on the debates on modernity/post-modernity, which AIDS also embodied.

Unlike the period of the Cold War, there is not much consensus in the characterization of current configurations of world politics and culture. With regards to our subject of the social production of knowledge about AIDS, the world has been idealized as a global partnership engaged in the pursuit of a common goal; however, it may also be presented as a complex, wary, and sometimes conservative universe of dissonant voices, as some of the U.N. sponsored global forums have shown. What channels of communication cut across that diversity and imminent cacophony? Who are the brokers in the process, and where does their social legitimacy come from?

If the social bridge that unleashed the process of science-making in the context of AIDS had originally been between an empowered social movement in the developed countries and its science agencies, what type of bridge should be expected between the centers of knowledge production and the vastly disenfranchised populations of the majority of the world? The global agenda of WHO, their traditional advocate, accounted for local empowerment and full participation for all. In chapter 3 we analyzed the role of WHO and other global agencies in spreading around the world the tools and models to act as fast and as efficiently as possible, not just in strict biomedical terms, but by promoting community empowerment as well. Was that agenda inclusive enough to account for a widely

expanded basis for the production of scientific knowledge, to promote bi-lateral partnerships between peripheral and central scientific settings? Could the distant voices from the third world be incorporated into the mainstream process of consensus making? To answer those questions it was necessary to conduct empirical research, preferably in a developing country.

From the very beginning, local actions against AIDS in the developing and peripheral countries had a source of strength in international agencies like WHO, which funded them and helped them take off. Except for New York City and California, which staged original social responses to the epidemic, action in most sites can only be analyzed as a combination of local characteristics and international aid. In chapter 4, I analyzed in detail the unique characteristics of one particular setting, that of Rio de Janeiro, Brazil.

The rich social movement responding to AIDS in Brazil from 1985 to 1995 cannot be understood without reference to the international movement and to the historical moment lived then by Brazilian society, which was overcoming two decades of military rule. Diverse and heterogeneous, the Brazilian AIDS NGOs movement tried unsuccessfully to create

organized networks and define common agendas for national intervention. From within that diversity, the most audible voices fought for generic civil rights and opposed the government systematically. In the post-military transition, the relations between the government and the civil society did not flow easily, and action upon AIDS was no exception. While many North American activists worked under the assumption that the government represented them and should execute their demands as citizens, Brazilians mistrusted their government as authoritarian, corrupt, and against the interests of the people. That radical opposition, matured in decades of authoritarian governments, was stronger than the availability for communicative action and interchange leading to any form of consensual knowledge; the universe of knowledge within which activists moved was irreducible to that of the government, and of the medical establishment, and vice-versa. Under these circumstances, the initial wave of activism in Brazil created, and became specialized on, its own channels of knowledge making. This production included a wide variety of media intervention and academic-style research. Some of the local production on social issues was acknowledged and adopted by international agencies.

In the medical settings, analyzed in chapter 5, the battles at stake were of another kind, and mainstream knowledge had to be handled on a daily basis. Due to the pressure of medical care, there was not much room to pursue original research questions, even though there were many local specificities that raised speculation and questions. The local world of infections and parasites diseases was different from the ones described in the literature, there were specific nutrition patterns, the health care system had its own form, there were local systems of belief which had an impact on the account of symptoms and their management, there might be idiosyncratic epidemic patterns due to local ways of transmission, and there were specific local political conditions. There was intellectual awareness of these issues, but the possibilities for turning them into research questions were limited. With a few exceptions, they could not be converted into scientific knowledge and became an input into the international system.

One exception was the inclusion of tuberculosis among AIDS pathologies. Tuberculosis had initially been identified by Brazilian doctors as a possible opportunistic infection for AIDS (e.g. Kritsky n.d.). In 1985, the hypothesis was dismissed by the CDCs as irrelevant (Paulo Teixeira, 1992, personal communication). At that time, tuberculosis was not seen as a public health problem in the

U.S., a fact associated with its temporary invisibility and the cutting of funds for its surveillance. Right afterwards, the disease came back to the U.S. inner cities and soon became a general problem, with serious implications related to multi-resistant variants. By then, the expertise of Brazilian doctors in the treatment of tuberculosis, which had long been irrelevant in the developed countries, became central for everybody.

The other exception is the adjustments in the AIDS case definition made by Brazilian and other South American health authorities. The revised versions, which allowed for a better adjustment to local circumstances, were incorporated by international agencies.

However, those two examples do not amount to a general transformation in the social basis of science making. Even though the local universe of AIDS experts was fairly cosmopolitan and visible, its participation in international settings was limited to sharing the consensual knowledge, rather than negotiating it. There is full and rapid access to international knowledge, but not necessarily in an interactive mode. Knowledge follows the traditional one-way, center-periphery route.

As the canon of what matters is defined by international, Anglo-American journals like the New England Journal of Medicine, Annals, or Lancet, so are the relevant questions and the relevant research. This fact leaves out

the problems that might be raised around specific clinical problems found in Brazil. They do not develop into full-bodied research problems, and much less so when the local actors are not trained to think of themselves as researchers, and have not mastered the idiom of research, or the know-how to develop original protocols, submit results and get them published. Participation in international research is therefore limited to joint ventures where the research questions and methods are defined by the "first-world" partner. These protocols often involve high-technology and expensive equipment, which themselves promote dependency and local differentiation.

Unlike the empowered AIDS activists in the U.S., local doctors involved with AIDS were not in a position to impose an original perspective on the subject. Local activists had done so for social issues, and at some level they addressed the question in epidemiology as well. However, clinical and basic research problems were rarely pursued by local social actors unless they were in pre-defined terms. There was no "global unleashing" of the knowledge-making process. Knowledge flowed throughout the globe, but through limited channels, and rarely in a multi-directional mode. Persuasion and hegemony, rather than a truly interactive dialogue, characterize the face of the "global" knowledge-making. Local creativity is transformed in clinical solutions which rarely translate into knowledge capable of

affecting mainstream science. Therefore, generalized participation in the fight against AIDS will not necessarily bring a significant shift in medical knowledge, which will tend to remain under the same paradigm and function as "normal science."

Data presented before chapter 6 provides a picture of dependent knowledge making, where "global efforts" are mostly rhetoric that succumbs to the dependency mechanisms of the use of high-technology in research. However, I had the chance to move beyond the field of AIDS-research and investigate other aspects of the rich tradition which had led me to choose Brazil test my questions: the field of immunology as it grew within tropical medicine, and the field of social epidemiology as developed under the analysis of health in dependent economies. Very close to AIDS, those two fields maintain original research tracks that constitute a challenge to current models for the understanding of this disease.

Social epidemiologists, who have elaborated complex models to account for the social determination of disease, have remained distant from the AIDS research bandwagon, where all the relevant variables are defined in terms of individual behavior. Mathematical models and statistical

projections based on those variables are more easily applied to immediate policies, and that is what epidemiologists working directly with AIDS have mostly done, including those in Brazil. Only now, and mostly due to reflections on the epidemic patterns in Africa, are some elements of social epidemiology included in a overall understanding of this pandemic.

As for basic medical research, outside the urgency and emergency-room atmosphere of clinical settings scientists pursue original questions on the immune-system, the physiology of lymphocytes, or interactions between cell and virus that could overcome the basic models that guide most research on AIDS. As illustrated in chapter 6, they work beyond the warfare model that characterizes the mainstream perception of AIDS and the immune functions. Instead, they emphasize the complex system network model that might shed a completely new light on AIDS and other immune disorders.

Why are these models not incorporated into basic research on AIDS, whether local or international? Maybe the time has not yet come. If there is any link between the ideologies that characterize the spirit of the times and the models that frame scientists metaphors and language, warfare is still the language of the day. Even if immunology is ready to replace its warfare paradigm by the cognitive network and flexible system imageries, it seems as though society is still quite comfortable with warfare.

Through the course of the AIDS epidemic we seemed to be moving out of a long historical period defined by war, hot and cold, into a middle range and centerless state of flexible accumulation and massified globalization. As we go through the 1990s, however, the mirage of a post-cold war era of openness, dialogue and peace has succumbed to increasing violence, scattered wars, ethnic cleansing and religious intolerance. Maybe science has plenty of models to replace the war paradigm, but society is not ready for that shift.

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