AIDS: A NEW PANDEMIC LEADING TO NEW MEDICAL AND POLITICAL PRACTICES

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Content

Dear Readers,

It seemed appropriate to assemble these texts now, at a time when the history of our AIDS missions is compelling us to formulate new goals. Until 1996, all we could do was to try to prevent and treat some of the opportunistic infections. Since then, the advent and large-scale distribution of antiretroviral drugs have turned the HIV field upside down, and the new drugs have brought new questions. At what stage of the infection should we start prescribing antiretroviral therapy? What should we do to ensure that every patient who needs treatment can get it, when millions still don't have access? How can we reduce the number of new cases? Can the epidemic be controlled in places where the HIV prevalence is very high?

The first text is taken from a book[1] on medical innovation in the specific context of humanitarian situations. It looks at the different attitudes adopted by MSF over the years in response to human immunodeficiency virus (HIV) epidemics, starting in the early 1980s and stopping at the end of the first decade of the 2000s, when millions of patients worldwide began receiving antiretroviral therapy. The second text picks up the thread of that story, but this time at the field project level, in the Homa Bay district of Kenya.

The last two texts offer an anthropological perspective on two issues discussed among the Homa Bay project teams: how caregiver team analyses connect the local culture to the spread of the epidemic, and the conditions for patient access to HIV diagnosis and treatment.

To this selection we have added a DVD with five films showing the different steps taken to implement preventive and curative treatments in Malawi since the early 2000s. A sixth documentary looks at issues of antiretroviral access in low-income countries from a political and economic perspective.

We hope this *cahier* adds to the conversation, as we prepare to refocus our strategies for practitioners in the field.

The Authors

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1. Bradol, Jean-Hervé and Vidal, Claudine (Eds.). (2011) *Medical Innovation in Humanitarian Situations: The Work of Médecins Sans Frontières.* MSF-USA.

PART 1
AIDS: A New Pandemic Leading to New Medical and Political Practices

Jean-Hervé Bradol and Elisabeth Szumilin

By the late 1990s the mortality rate for the human immunodeficiency virus (HIV) had been brought under control in high-income countries, thanks to the combination of several antiretroviral drugs. Yet there was no plan for administering the treatment in the world's largest foci of infection. Sub-Saharan Africa in particular, the most seriously affected region, was not benefiting from therapeutic advances. Refusing to accept this situation required innovative efforts on two fronts: medical and political. In 2008, 140,000 people, ten thousand of them children, received free generic antiretroviral drugs in projects supported by MSF. After a limited number of laboratory tests, patients are prescribed fixed-dose combination treatments (in a single tablet) by non-specialist doctors or nurses. If there are no complications, the prescriptions can sometimes be renewed by public health technicians.[2] Treatment of opportunistic infections is available wherever possible, and treatment for tuberculosis, the leading cause of death among AIDS patients in Africa, is integrated with HIV treatment. During the first few years of treatment, survival rates are similar to those obtained in North America and Western Europe. Does this qualify as a success? Only a sustained reduction in the number of deaths and the number of people carrying the virus in the hardest-hit regions will show the true effect of the changes that have occurred in recent years. This article presents the circumstances and reasons which led MSF to treat patients who would not otherwise have access to new and costly treatments.

THE RIGHT CIRCUMSTANCES, AND A CERTAIN INDIFFERENCE

According to the World Health Organization (WHO), "The human immunodeficiency virus (HIV) is a retrovirus that infects cells of the human immune system, destroying or

2. As compared with France, where fewer than ninety thousand people receive Affection de longue durée (long-term illness) health insurance for AIDS and only specialist physicians can prescribe antiretroviral therapy. See www.sante-sports.gouv.fr/IMG//pdf/03_Epidemiologie.pdf (in French).

impairing their function. In the early stages of infection, the person has no symptoms. However, as the infection progresses, the immune system becomes weaker, and the person becomes more susceptible to opportunistic infections. The most advanced stage of HIV infection is acquired immunodeficiency syndrome (AIDS). It can take ten to fifteen years for an HIV infected person to develop AIDS. Antiretroviral drugs can slow down the process even further. HIV is transmitted through unprotected sexual intercourse (anal or vaginal), transfusion of contaminated blood, sharing of contaminated needles, and between a mother and her infant during pregnancy, childbirth, and breastfeeding."[3]

A look at the advance in knowledge on HIV from the early 1980s to the mid-1990s shows that discoveries were made quickly (Grmek, 1990). Clinicians began to suspect the existence of a new disease in 1981. In 1982, transmission of the disease to hemophiliacs via blood products that, despite filtering, transmitted the infectious agent suggested a very small micro-organism: a virus. In 1983, HIV was classified as a member of the retrovirus family because of its mode of replication. It was cloned in 1984, and its genome was identified. The identification of HIV antigens led to a blood test that—within certain limits of sensitivity and specificity—could confirm or rule out the presence of HIV (1985), making it possible to prevent transmission through blood transfusions. The test identified those who carried the virus and those who did not. It then became possible to discern better how the virus spread within populations, and to identify the most seriously affected regions and the highest risk groups and behaviors. This helped define and measure the effect of the preventive actions that were being introduced in high-income countries in the late 1980s. Understanding the retroviral mode of replication led to the use of the first drug, Zidovudine, whose efficacy is relative and temporary (1987). Prevention of mother-to-child HIV transmission and administration of a treatment against the virus itself became possible. Knowing HIV's genetic makeup also led to measurement of the viral load in the blood—a key laboratory indicator for monitoring treatment efficacy. Genetics also enabled identification of mutant viruses resistant to certain drugs, making it possible to avoid ineffective antiretrovirals right from the start of treatment. Understanding the virus' predilection for certain blood cells involved in the immune response resulted in a test that could measure HIV's effect on the body's immune defenses, the T4 lymphocyte level (CD4 test). At the same time, different strains of the virus (HIV-1, HIV-2, etc.) were identified. Roughly fifteen years separated the first clinical diagnoses (1981) from the prescription of a treatment transforming an almost-always fatal disease into a chronic one (1996).

The 1983 International AIDS Conference in Denver saw the emergence of a political movement for people living with HIV. At the 1989 Montreal Conference, ACT UP and its Canadian counterpart, AIDS Action Now, manifested their presence as soon as the opening ceremony started. They demanded that research focus on patients' needs rather than on pharmaceutical industry interests alone. In 1994 the principle that organizations of people

living with HIV should have greater participation in the fight against AIDS was adopted by forty-two countries at a summit in Paris. In 2008 the Global Network of People living with HIV (GNP+) included more than a thousand member organizations. They demand participation in all institutional processes regarding the fight against AIDS, call for universal access to prevention and treatment programs, and emphasize prevention targeting those who are HIV-positive. They also call for more information on sexual and reproductive health, are opposed to criminalization of virus transmission, and defend the rights of people living with HIV.

In 1989 MSF-France's Board of Directors approved a proposal to participate in the Montreal AIDS Conference, and MSF-Belgium opened a free, anonymous testing center in Brussels. The MSF delegate to the Montreal Conference declared that it was "unthinkable to him that Médecins Sans Frontières should not be involved in the response to AIDS." He suggested possible approaches involving education, treatment, epidemiological surveys, and palliative care. He reported that treatments were being developed "based on very complex and very expensive combinations" and, among the avenues of research, he noted that there were "openings in Africa on mother-to-child transmission. … A long debate began between those who thought that Médecins Sans Frontières could and should conduct AIDS related activities, and those who thought it was not within the organization's scope."[4] The debate was lively and tense. Advocates of engagement emphasized the large number of deaths in certain social categories and certain areas of the world—Africa in particular. They spoke of possible prevention activities and treatment approaches. Those resistant to the proposal stressed that there were no drugs available, and that prevention activities relying primarily on persuading people to change their sexual behavior had very doubtful outcomes. In their view, MSF—a foreign organization with little mastery of the languages needed for disseminating information and a superficial approach to local culture—was not the institution best-suited to do work that was more social than medical. The first report on AIDS, written by Epicentre[5] for MSF in 1990, concerned the situation in France: "MSF is frequently asked to intervene on AIDS in France. Yet no one in the organization is particularly responsible or expert in that area, and MSF has no policy on the subject."[6] The requests were coming from patient organizations, researchers, and practitioners hoping that MSF would support their cause with its resources and reputation. A large diversity of opinions emerged among the governing bodies at MSF. Over the 1980s, these bodies had developed into a movement of different national sections (Belgium, Spain, Greece, Switzerland, Holland, etc.). The relative political indifference at the office in Paris was met with internal opposition that had a lot of support from other national sections.

In missions outside France, the growing awareness of how health care facilities were responsible for the spread of AIDS led to a series of measures aimed at preventing virus

4. Report from the MSF-France Board of Directors meeting, June 30, 1989.
5. Epicentre is an MSF satellite organization that specializes in the epidemiology of intervention, research, and training.
6. Philippe Malfait, Mission MSF et sida en France, Epicentre, January 25, 1990.

transmission during medical procedures. In June 1993 the medical department at the Paris headquarters informed the Board of Directors that screening tests were being set up at sites where MSF was directly responsible for transfusions. While members of the Board are not directly in charge of sensitive activities (sterilizations, transfusions, injections, surgery, etc.), this work is nevertheless dependent on them. An unanticipated diagnosis before transfusion, coupled with the fear of stigmatization and discrimination and no offer of treatment, has sometimes meant that testing was delayed. Studies of serological prevalence among pregnant women (Uganda and Sudan) sparked a debate on the appropriateness of informing a woman that she is HIV-positive during a routine pre-natal consultation. "What should we do with someone whom we've informed, after our testing, that she is HIV-positive, or with a patient? We risk condemning people to a faster and more painful death, because that knowledge will get them ostracized from their community."[7]

Antiretroviral drugs made their first appearance in an MSF HIV prevention kit in the mid-1990s, following an accidental occupational exposure to blood. Mutual aid was also discreetly provided to infected colleagues, friends, and lovers. MSF employees with opportunistic infections were given access on an individual basis to treatments that were unavailable, and often very expensive, in their own countries. Ad hoc networks sprang up to stay with dying friends and loved ones. Refusals to grant visas on the grounds of seropositivity were circumvented with the organization's complicity. Later, when the first triple therapies appeared, they were sent "under the counter" to colleagues in countries where they were unavailable. Such actions were limited in number, but they highlighted the fact that MSF needed to get involved in treating the disease. One of the very first field projects (Surin, Thailand, 1995) that focused on treatment, rather than prevention, was started by an expatriate nurse who had spent several years supporting Thai friends in the terminal stage of the disease. From such individual acts, carried out in the belief that therapeutic solidarity was morally legitimate, emerged a sense of political affinity among those who strongly opposed an institutional position they considered overly timid, and who were willing to change MSF's policy. Some members of MSF hoped for public advocacy and the large-scale use of antiretroviral drugs as a way to reconcile individual experience and institutional action.

The epidemic was particularly severe in places (eastern, southern, and central Africa) where MSF had developed its original, non-AIDS-related hospital activities. The medical teams were faced with a growing number of cases involving difficult-to-treat opportunistic infections and management-intensive terminal patients. The teams also had to deal with local staff who were not informed of how the virus was transmitted, and who refused to care for patients for fear of infection. MSF team members mobilized to improve patient welcome and disseminate basic knowledge on transmission and prevention with information and professional training sessions. Practical objectives included welcoming

7. Report from the June 1989 Board of Directors meeting, Paris.

patients, treating opportunistic infections, and providing palliative care (pain, wounds, nutritional support, personal hygiene, psychological and social support). Antiretroviral drugs are therefore essential. Without them, treatment is difficult and ill adapted, and neither reduces the body's viral load nor restores the immune system. This was an argument for their use.

Prevention activities in the field increased among specific groups, such as prostitutes and truck drivers in Mwanza, Malawi, despite the reluctance of some, who wanted to focus mainly on treatment. In late 1995 an editorial on the cover of MSF-France's in-house magazine Messages asked, "MSF: a white, heterosexual, HIV-negative organization?" It was a provocative title designed to promote prevention activities and patient support, and fight against stigmatization and discrimination. Such activities were not widely adopted by MSF-France, but began to flourish among other sections. By 1998 MSF was able to claim "48 field projects in which AIDS is a major component." Without an effective treatment, however, the fight against discrimination and in favor of prevention was not enough to make AIDS a core concern in MSF's policy.

DRUG PRESCRIPTION: HESITATIONS AND AUDACITY

At the opening ceremony of the 1996 International AIDS Conference in Vancouver, the New York representative for ACT UP raised the issue of access to treatment for the hardest hit populations. "Yes, the preliminary results from these hugely expensive combination treatments look great. But we are a long way from a cure, even for the rich who can afford the treatments. And we are no closer to a cure for the majority of people living with AIDS on this planet than we were ten years ago. Most peoples living with AIDS can't get aspirins."[8]

At the 1997 Abidjan Conference, the French president and the minister of health called for "international therapeutic solidarity." In June 1997, with support from a few multinational drug companies and the World Bank, the Joint United Nations Programme on HIV/AIDS (UNAIDS, created in 1995) launched the HIV Drug Access Initiative (UNAIDS-DAI). The DAI relied on some of the big pharmaceutical firms agreeing to differential pricing according to a country's income level, whereas these firms previously asked a single price worldwide. In 1998 several countries (Uganda, Senegal, and Ivory Coast) began using triple therapy in their public programs. Its virological efficacy was

8. http://www.actupny. org/Vancouver/sawy erspeech.html.

established in the initial reports. These early experiences using triple therapies in resource-limited countries proved their feasibility and efficacy. Some of the practical aspects (the lack of generics; prices that were still too high; asking patients to contribute to the cost; the lack of fixed-dose combination of three antiretroviral drugs in a single pill; the significant clinical, laboratory, and psychosocial follow-up needed; etc.) were only compatible with cohorts of several hundred patients, however, at a time when tens of thousands of patients were waiting for the simplest, least expensive treatment.

The small number of patients treated by the UNAIDS accelerated-access initiative contrasted with the experience in Brazil, whose national program—using generics and free medications—rapidly treated nearly 100,000 patients (170,000 in 2008). In 1996 Brazil launched a public treatment program by presidential decree. Brazilian patent law allows for compulsory licensing (without the patent-holder's consent) to produce generic drugs, so while the public pharmaceutical company Pharmanguinhos (Oswaldo Cruz Foundation) does not manufacture all antiretrovirals itself, the possibility of doing so—should a private firm's price be considered too high—creates a credible threat of competition that lowers prices. Brazil stands out because it was the first low- or medium-income country to treat large numbers of patients, and remained the only one to do so until the mid-2000s. MSF reached an agreement with Brazil's public institutions to export Brazilian antiretrovirals to South Africa. Apart from this agreement, Brazil has never supported the effort to treat patients in very poor countries by exporting generics,[9] though it does assist them in developing their own production.

The high cost of the triple therapies used by Brazil (about $3,000 per patient per year) made large-scale initiatives by other countries highly unlikely. In February 2000 the Indian pharmaceutical company Cipla[10] announced that it would be marketing a combination treatment, Triomune, for $350 per patient per year. Its components were chosen based on efficacy, the amount of time until certain side effects appeared, and, above all, the price of raw materials.[11] The aim at the time was to offer it at the lowest possible price: $650 per patient per year, as opposed to several thousand dollars. Cipla granted MSF an additional $300 discount, which was ultimately extended to all customers. It was not in the economic interest of the patent-holders of each individual drug to manufacture a single pill, so producing generics without a patent made it possible to produce the triple therapy. This was the first time patients throughout the world had access to such a simple treatment—three antiretroviral drugs in a single tablet, morning and evening. Triomune's low price and ease of use opened the way for public health programs on a national scale.

At the same time, in Africa, private companies from various sectors (mining, energy, beverage, automotive, etc.) began funding access to antiretroviral drugs for their employees. Held in one of the most seriously affected countries, the July 2000

9. The World Trade Organization (WTO) has allowed countries to manufacture generic drugs legally for public health reasons, but the possibility of sending these generic drugs to other countries where they are covered by patents is unclear.

10. Cipla's creation in 1935 expressed the nationalism of its founder, Khwaja Abdul Hamied. The company was honored by a visit by Mahatma Gandhi in 1939.

11. Telephone interview with Dr. Yusuf Hamied, Cipla chairman and CEO, January 23, 2009.

International AIDS Conference in Durban was a high point in improving access to treatment. It was at this venue that Merck, the pharmaceutical giant, and the Bill and Melinda Gates Foundation announced their $100 million donation for a treatment program in Botswana. The hype surrounding these philanthropic actions masked the essential fact that even the least expensive triple therapies, available through UNAIDS, were nevertheless still very costly (between $800 and $1,000). Information obtained from the pharmaceutical industry, and confirmed by a WHO expert, prompted MSF to publish the report HIV/AIDS Medicines Pricing (Perez-Casas, 2000), which showed that it would be possible to reduce the cost to under $200 per patient per year.

Procuring the drugs and getting them to the field meant clearing a dual pharmaceutical and legal hurdle (Boulet, 1999). No internationally recognized reference institution could guarantee the quality of the supply source alternatives to the pharmaceutical multinationals. Buyers were unlikely to be reassured by generic triple therapies from India, which were not marketed in either the US or Europe. MSF criticized the WHO for not taking responsibility; humanitarian pharmacists had to visit and validate manufacturing sites themselves in order to choose suppliers. In 2001 MSF began publishing an international guide to purchasing antiretroviral drugs for developing countries (the Campaign for Access to Essential Medicines, MSF, 2008). MSF-Logistique's legal status as a pharmaceutical establishment facilitated transit through Europe and redistribution in several dozen countries. To manage the risks involved in purchasing, storing, importing, and exporting generic triple therapies, MSF recruited a team of lawyers and pharmacists specialized in intellectual property issues, administrative registration, supplier selection, and drug marketing.

Just because a treatment is available on the market does not mean that authorities will automatically approve—or medical teams support—its use. Obtaining official authorization and convincing medical teams of the benefits means that new products need to be incorporated into a treatment protocol that is realistic both in terms of the patients' circumstances and the caregivers' professional practice. How to simplify without sacrificing efficacy? That was the task of the staff at MSF's medical departments, charged with providing technical support for field teams, with backup from experts at university medical centers. Some of the doctors who undertook this technical adaptation had continued to take short-term assignments in hospitals in Europe, Japan, Australia, or North America, and had been prescribing triple therapy for several years. With their experiences in resource-limited countries in mind, they were convinced that the protocols could be simplified without sacrificing the practices essential to therapeutic efficacy. Brazil had already proven that it was possible to prescribe antiretroviral drugs in middle-income countries, and others were following the same path, particularly Thailand. There were strong reservations, however, about sub-Saharan Africa, which, over the past decades, had

suffered increasing poverty, political instability, and the collapse of public health institutions.

There were some parameters the medical team could control, such as prescription quality and drug management, but if patients didn't take medication regularly, failure was inevitable. From an individual stand point, patients facing imminent death would have more to gain by trying a treatment that is risky; but a poorly controlled program and bad treatment compliance (creating resistant strains of the virus) would compromise the future of treatment for the population as a whole. For this reason, the patient's ability to come for check-ups (distance, available transportation, and budget) was an essential criterion for acceptance into the group receiving triple therapy. A strict treatment protocol means more than just coming in for checkups, however. The patient must also understand, or at least accept, the medical reasons underlying the protocol. The MSF medical team decided to focus on providing information to the patients using specialized medical counselors, and a member of the patient's social circle was chosen and trained to encourage daily adherence to treatment.

Lab testing was also a tricky issue. Existing knowledge suggested starting antiretroviral drugs when the immune response was markedly weakened, but lab tests were not readily accessible to MSF teams. Other tests to evaluate the function of potential target organs for side effects were also needed. Monitoring treatment efficacy would have required lab tests to measure viral replication in the body (the number of viruses per unit of blood, or viral load). In a professional setting dominated by the idea of evidence-based medicine which often relies on the measurement of biological markers, initiating treatment based on a marked deterioration in immune defenses, ensuring its efficacy, and preventing its toxicity without the help of lab tests seemed dangerously experimental.

Once the protocols were defined and administrative authorization obtained, there were still several concerns hindering prescription. Would the fact that there were only a small number of treatments available for a large number of patients lead to tensions, violence, or crime? Should priority be given to people who were needed to treat others (doctors, nurses, etc.), or even to those who performed essential societal functions (political leaders, teachers, etc.)? Decisions to launch field projects were based on several criteria: the local prevalence of AIDS, the attitude of public health officials (whether they were open to the use of antiretroviral drugs), and MSF's institutional interests. Treatments were administered to patients who were already frequenting outpatient clinics and hospital services, with priority going to those whose condition was most critical. Medical staff would be among the first to receive treatment due to their proximity with those prescribing it. Tensions did exist, and MSF sometimes hesitated to treat its own staff. The impossibility of delegating the treatment of MSF personnel to specialized institutions,

which were largely non-existent, was a convincing argument. Being able to prescribe such complicated-to-manage treatments simultaneously in the dozens of countries where MSF intervened was difficult. Some in MSF's leadership feared that adopting an official resolution in favor of treating staff when there was no treatment mechanism in place might expose the organization to legal action by employees. Finally, in November 2002, the MSF International Council decided to guarantee MSF employees access to antiretroviral treatment.

POLITICAL DYNAMICS

By the early 1990s infectious diseases had again become a priority in international relations due to their potential economic and security repercussions. The emergence of new epidemics (Ebola and AIDS, in particular) and the fear of bioterrorism spurred governments to step up their disease related activities. Many institutions (national governments, international organizations, pharmaceutical firms, national and international private organizations, religious institutions, unions, political parties, etc.) were faced with the dilemma of how to respond to the AIDS pandemic. The Internet played a key role in relationships that transcended borders, spreading to the most peripheral players (patients, caregivers, citizens), and reaching the top of public health, economic, and political institutions. Until then, the issues of drug access had been examined behind closed doors, and were the exclusive domain of experts, manufacturers, and government representatives. Henceforth, the discussion enjoyed broad media exposure. AIDS organizations and medical organizations like MSF took their place at the negotiating table. The medical and political dynamics challenged interpretation according to institutional positions or individual opinions based on their own interests. The strong feelings around the disease changed the usual dividing lines between individuals and institutions. We can define three basic attitudes: realism, universalism, and caution.

The realists argued that the conditions necessary for increasing the number of people treated from a few hundred thousand to several million did not exist. Drug availability by itself could not make up for the patients' lack of schooling, the shortage of qualified personnel and equipment, the meager budgets and inadequate management of health care institutions, or the poverty and instability of the hardest-hit countries. Why make a special effort for AIDS and not for other diseases that were just as prevalent, even more deadly, and far easier to treat? MSF, an emergency-oriented organization, would not have the

expertise and constancy that were essential for a lifetime commitment to the patient. There was a serious risk that drugs would be used incorrectly and that mutant, antiretroviral resistant strains of the virus would rapidly emerge. Prescribing before conditions were right would compromise the ability to introduce treatment under more favorable circumstances in the future. Another perverse effect—a drop in prices, and, more importantly, a weakening of intellectual property rights—would discourage research and development funding for new drugs. The prospect of a return on investment would be undermined by black market imports of low-price generics competing with patented drugs in viable markets, and by an erosion of profit margins in emerging markets due to lower, differential pricing based on country income. Charitable donation was proposed as the only suitable method in the rare situations where conditions were right for using triple therapy. At the 2000 International AIDS Conference in Durban, Merck announced that it would supply two antiretroviral drugs free of charge for the national treatment program in Botswana. In that country, where one in four adults (fifteen to fifty years old) carried the virus, realism, faced with a potential demographic catastrophe, met its limits.

Universalists advocated making AIDS treatment accessible to everyone. Public health policies could not be restricted to priority groups dictated by disease statistics. Indeed, societies' reactions to the pandemic, whether rational or not, would be an opportunity for poorly functioning health care systems to use the fight against AIDS as a starting point for recovery. Generally speaking, the universalists characterized any objection to making HIV treatment immediately accessible as an obstacle to be overcome. The MSF representative who participated in the parallel meetings at the 1999 WTO Ministerial Conference in Seattle declared that patients were dying not from AIDS, but from the unavailability of drugs due to the patent system. This reasoning, without limiting it to the realm of intellectual property alone, supposes a change in attitude by governments, the pharmaceutical industry, the medical profession, and patients.

Where the universalists saw obstacles to overcome, the cautious needed guarantees before taking action. Precautions had to be taken in order to satisfy not only the moral imperative to treat, but also the need to do no harm, and to avoid squandering available resources and compromising the future. So prescribing HIV treatment was considered, but on a smaller scale and in countries that already had some means (Brazil and Thailand, for example) and depending on the environment (patents, the policy of patient contribution, limited human and material resources, etc.). The first use of antiretroviral drugs in Africa on the initiative of UNAIDS, and the first MSF protocols, illustrate this cautious approach.

All three attitudes brought morality, medical science, public health, economic rationalism, and political will to bear in their arguments; all three wanted to be universal, realistic, and cautious at the same time. In practice, however, they were mutually

contradictory. Compromise was essential, but finding the perfect balance was impossible. MSF was a good example of this dynamic plurality of opinions that changed as a function of many variables, some more heavily weighted than others: the emergence of triple therapy, the will of governments, social and political mobilization, the changing application of intellectual property rules, the drop in antiretroviral prices, the availability of public funding, the analysis of the early experiences in the field, scientific publications, public controversies, and each institution's own interests.

Governments, international organizations, pharmaceutical firms, and local associations were all involved in a national and international political dynamic that exposed their contradictions, obliged them to explain themselves publicly, and forced them to make decisions that, until previously, they had considered contrary to their intentions and their interests. In May 2000 President Clinton supported the countries of sub-Saharan Africa that wished to produce and import generic drugs (Executive Order 13155). In July 2000 at the United Nations (UN) Security Council meeting and the Group of Eight (G8) summit in Okinawa, two important commitments were made: "mobilizing additional resources" and "addressing the complex issue of access to medicines in developing countries, and assessing obstacles being faced by developing countries."[12] The terms "access" and "obstacles" in the final G8 resolution were borrowed from the vocabulary of non-governmental organizations, including MSF, that were involved in preparing the Okinawa summit. Then UN Security Council Resolution 1308 (2000) stressed that "the HIV/AIDS pandemic, if unchecked, may pose a risk to stability and security." The World Bank described AIDS as a "development crisis."

After the failure of the WTO Ministerial Conference in Seattle (1999) there was strong pressure to ensure that the Doha Conference (2001) provide a solution to the crisis. The question of access to drugs seemed to offer the possibility of a positive outcome for at least one of the issues being negotiated internationally. The monopoly granted to patent holders for marketing their drugs was weighing heavily on prices; in the late 1990s, triple therapy cost between $10,000 and $15,000 a year. Therefore, what was needed was to make application of the Trade-related Aspects of Intellectual Property Rights (TRIPS, 1994) agreement more flexible, so that the management of patents would not conflict with the production and circulation of less expensive generic medications, considered essential to public health. Brazil, India, and Thailand led a group of about sixty countries in which Africa was heavily represented. They worked for access to generics, and were backed by several hundred national and international organizations, including Oxfam and MSF. For some countries with limited legal and pharmaceutical expertise, the alliance with advocacy organizations meant the possibility of receiving technical assistance. The organizations linked their technical assistance with lobbying for their political proposals. Countries concerned with defending intellectual property rights (the United States, Japan, and

12. G8 communiqué, Okinawa, Japan, July 2000; www.g8.utoronto.ca/ summit/2000 okinawa/finalcom. htm.

countries in the European Union, in particular) wavered between strengthening and softening the rules. They feared that by rejecting an agreement authorizing production and circulation of generic drugs, they would spark reactions jeopardizing the entire newly created TRIPS agreement. A few months before the Doha Conference, and in view of the Pretoria trial,[13] US Trade Representative Robert B. Zoellick tried to get the pharmaceutical firms to see reason: "If they don't get ahead of this issue, the hostility that generates could put at risk the whole intellectual property rights system" (Blustein, 2001). Not all manufacturers were on the defensive, however. Indian companies producing generics were poised to take over the large market expected to result from the change in WTO policy. At Doha, the Ministerial Conference affirmed the sovereign right of nations to take measures to protect public health. Among other things, the Doha Declaration made it possible for a country to manufacture drugs without the patent holder's consent (compulsory licensing), providing royalties were paid ('t Hoen, 2009). It authorized importation from a country where prices are lower (parallel imports) without the manufacturer's or patent holder's permission. It was another two years before the issue of parallel imports of generic drugs under compulsory license was addressed, on August 30, 2003, in Geneva, with the establishment of fairly restrictive procedures. Despite the limits of the measures adopted, and the pressures exerted to curtail their application, the competition created by the arrival of generics on the market brought a radical drop in prices, which fell 99% between 1999 and 2007.

The organizations advocating universal access to antiretroviral drugs timidly began prescribing them. By November 2001, 650 patients were receiving antiretroviral drugs in all MSF projects combined. The evolution from prevention to treatment met with so much internal resistance that, in November 2002, the MSF International Council adopted a resolution prohibiting AIDS projects that were limited to prevention and did not include the use of antiretroviral drugs. Due to caution, treatment protocols were so restrictive they drastically limited the number of patients treated. MSF then relied on the experience of other prescribers (the Burundian Association Nationale de Soutien aux Séropositifs et Sidéens, and Paul Farmer's teams in Haiti) to increase rapidly the number of patients treated. From 2003 to 2004, MSF doubled the number of patients receiving antiretroviral drugs in its projects, from five thousand to eleven thousand.

In June 2001 a special session of the UN General Assembly recommended the creation of an international fund to finance the fight against the AIDS pandemic. The Global Fund to Fight AIDS, Tuberculosis and Malaria was created in 2002, awarding its initial funding to thirty-six countries. That same year, the WHO added antiretroviral drugs to its list of essential medicines. The "3 by 5 Initiative" (three million patients on antiretroviral drugs by 2005), launched in 2003 by the WHO and UNAIDS, was a major step toward providing access to AIDS treatment. Though pleased by these developments, MSF voiced some

13. In 1998 a coalition of about forty pharmaceutical firms filed suit in South Africa to try to prevent the application of a South African law, passed by Parliament in 1997, allowing the production of generic drugs. The cases were abandoned in 2001 under pressure from public opinion.

reservations regarding the absence of what it considered essential recommendations. Many in the organization believed that the use of generic drugs was not being promoted, despite the fact that generics would allow many more patients to be kept alive for the same amount of money. Some members also pushed for generics containing several drugs in one tablet, which simplified the treatment regimen for the patient, thus ensuring better treatment adherence and efficacy. MSF was also critical of the fact that the "3 by 5 Initiative" did not advocate either free treatment for patients or the right for nurses to prescribe drugs, when the limited number of practicing doctors made it impossible to treat several million patients.

In 2003, the US President's Emergency Plan for AIDS Relief (PEPFAR) was launched. The plan included the dispensing of antiretroviral drugs, which the US administration had, until recently, considered impracticable in Africa. In an article in the Boston Globe on June 7, 2001, Andrew Natsios, administrator of the United States Agency for International Development (USAID), was quoted as saying that "many Africans don't know what Western time is. You have to take these [AIDS] drugs a certain number of hours each day, or they don't work. Many people in Africa have never seen a clock or a watch their entire lives." Scientific arguments were needed to make the case, so Epicentre created a database (FUCHIA) of all patients treated by MSF for HIV infection. Beside their usefulness in guiding actions, the analyses produced from the database have enabled MSF to publish in scientific journals, thus legitimizing its contribution to the public debate. The international mobilization and the publication of early results on survival rates among African patients on antiretroviral drugs[14] dismissed the Bush administration's initial reluctance (Kasper et al., 2003; Ferradini et al., 2006). At a meeting with MSF representatives, Randall L. Tobias, coordinator for the president's AIDS initiative, maintained that the results obtained by several teams, including MSF's, made inclusion of antiretroviral funding inevitable in the president's plan.[15]

The number of people receiving antiretroviral treatment in low- and middle-income countries increased from three hundred thousand in 2002 to three million in 2007. Yet only a third of patients needing treatment were receiving it in 2007. That same year, 2.5 million people were newly infected, and more than two million died of AIDS. The specific needs of children—in terms of both prevention and treatment—are still only poorly covered. The treatment available today is complicated, has severe side effects, and must be taken for life. In addition, the data on the efficacy of national treatment programs is fragmentary. Globally, 18% of treatment sites that provided information have experienced at least one inventory shortage of antiretroviral drugs (WHO, UNAIDS, UNICEF, 2007, p.4). The lab test that helps assess treatment adherence and efficacy is rarely available for individual monitoring. A few epidemiological surveys make up, in part, for the lack of information on the success rates of treatment programs in precarious settings.

14. The early results were made public during an oral presentation at the International AIDS Conference in Barcelona (summer 2002).
15. Report from the January 7, 2004, meeting with Randall L. Tobias, MSF archives.

Today, due to their toxicity and limited efficacy, the antiretroviral combinations in use in middle- and low-income countries are no longer prescribed in high-income countries. The flexibility in intellectual property rules that made a first-generation treatment possible in resource-limited countries in no way guarantees that these countries will get new drugs, the need for which is already being felt. Nor is there any guarantee that the funding available for fighting AIDS will continue. Therefore, roughly twenty years after discussions began, voices are once again being raised, both within MSF and elsewhere, urging innovation rather than resignation.

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PART 2
AIDS: from initiating treatment to fostering patient loyalty

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This document is the result of a visit in July 2010 to the MSF Homa Bay project in Kenya's Nyanza Province and part of a study launched in 2009 on the future of MSF AIDS projects. The past two years have seen tense debates among the teams regarding future directions. Sharp exchanges – and sometimes needless humiliation – have left their mark on the people involved, both in Kenya and at Paris headquarters. This atmosphere reflects the bitter reality of the discussions on the directions to take and the power issues seen in any institution. The visit was useful, however, thanks to the resolve of all those concerned to prevent a useful debate from turning into a series of squabbles. The visitor was thus able over a period of about ten days to familiarize himself with the principal work situations and issues faced by the teams. The author has been going to Kenya for some twenty years, and has been visiting the MSF clinic serving the population of Nairobi's Mathare slum since 1998. The clinic's activities now centre on HIV, tuberculosis, and women victims of sexual violence. The focus of attention on this visit was the Homa Bay project, which covers two districts (Homa Bay and Ndhiwa) in Nyanza Province. As the project grows and evolves, the question of HIV treatment coverage for all those who are medically eligible is posed.

The internal discussions on the future of HIV projects were woven together from a number of topics, which can be grouped into three sections: the setting (local, national, and transnational) in which MSF works, the role it would like to play in the fight against HIV, and how it manages its AIDS projects. Once back in Paris, the challenge was not to tackle all the issues, but rather to examine certain important points that keep coming up in discussions, while trying to find openings where the assumptions and formulation of questions in the debate wouldn't lead to the same impasses.

> A field project is a set of activities aimed at meeting objectives in a given place or institution (for example, an administrative department, a town, a camp, a hospital or any other medical or social institution).

Each field project is run by a national or international team under the authority of a field coordinator. At the national level, projects are overseen by a capital team, led by the Head of Mission. For each member of the field team there is a double chain of command, political: (Field Coordinator, Head of Mission, Desk Programme Manager, Operations Director, Executive Director, President, and Board of Directors) and professional: (for example, Doctor, Field Medical Coordinator, Capital Medical Coordinator, Desk Medical Advisor, and Medical Director).

The desk is a subdivision of the Operations Department under the authority of the Operations Director. It is responsible for steering the projects, choosing among the different possible activities, and monitoring them from headquarters. It is led by a Programme Manager and consists of several representatives from the professions needed for operations (medical technology, human resources, administration, and logistics). See the sheet on the Kenya project, 2010, in the appendices.

THE LOCAL, NATIONAL AND TRANSNATIONAL CONTEXT

THE PANDEMIC, AS SEEN FROM KENYA

The 2007 national survey already showed an average prevalence of just over 7% for Kenya's adult population (ages 15 to 64). However, HIV prevalence was 15% in Nyanza Province, yet less than 1% in the North Eastern Province. In one province AIDS is a health catastrophe, in the other just another disease. In some places, the epidemic has never assumed tragic proportions. In Kenya, as in other countries, the situation is still disastrous for large segments of the adult population living in high prevalence zones and for groups of individuals whose practices not only put them at greater risk of infection, but make them less likely to receive care, due to the disapproval they elicit (men who have sex with other men, prostitutes, drug users, etc.). But the discrepancy between available resources and the large number of cases as well as the stigmatization of certain lifestyles are not the only reasons why some people are excluded from treatment. Patients with severe forms of the disease and children – whose needs differ from those of the majority of patients, who are adults – are penalized by care poorly-adapted to more complex and expensive protocols.

The term "pandemic" – an epidemic progressing within a very wide geographic area, over several continents – is more a social and political necessity for mobilizing epidemic response than it is a solid epidemiological concept. Should we measure it by the proportion of the world population that is infected? The resulting morbidity and mortality? In 2009, when asked to give a precise definition of the term "pandemic" during the debate over public expenditures for H1N1 flu outbreaks, medical experts – the WHO leading the way – were hard-pressed to come up with an answer. The way that politicians and activists use the word "pandemic" suggests there's a single reality encompassing all the various epidemics; that there's an invisible thread connecting San Francisco's backroom regulars with the patrons of Kinshasa's brothels. Politically, the feeling of a shared fate with respect to the disease has unquestionably paved the way for international solidarity. It has helped provide wider access to a treatment that was at first available only to a privileged few – patients in wealthy countries. But for all that, being infected by the same virus doesn't create a common interest, or indeed a common destiny, between such geographically and socially disparate people. Even within the same country, the epidemiological profile and daily lives of IV drug users set them apart from the rest of their HIV-positive fellow citizens.

THE PACE OF KNOWLEDGE ACQUISITION AND MUTATIONS IN FUNDING

One argument used to convince donors to continue their efforts is that, despite the emergency situation, the response is slow and inadequate. The fact that the available drugs and protocols cannot stop the spread of the disease or treat all of the patients contributes to the feeling that research is not progressing. In reality, there has been rapid progress in knowledge and know-how since the defining of the new syndrome in 1981. The disease was quickly understood to be caused by a virus (1982) belonging to the family of retroviruses (1983). The virus was cloned, and its genome decoded in 1984. Soon the first laboratory test for confirming diagnosis became available (1985), and the first drug, zidovudine (AZT), was proven effective (1987). A treatment capable of extending life by several years (HAART) was identified in 1996. In roughly ten years (2001-2010), five million people were treated with antiretroviral drugs, despite the fact that the vast majority of them lived in low- or middle-income countries.

The past three decades have seen the burgeoning of prevention and treatment initiatives on a scale and pace unheard of in the history of public health. So should we assume that biomedicine is now so expert and so powerful that we can expect equally profound and rapid advances in coming decades? The fact that MSF programmes were using HAART barely five years after it was proven effective is remarkable. It usually takes longer; humanitarian doctors often have to wait twenty years or more before being able to use a new treatment. While major strides have been made, we still don't have a vaccine to prevent infection, or a drug capable of completely eliminating the virus from the body.

And while prevention and treatment tools reduce the number of new cases and slow the progress of the infection, they are still ill-suited to living conditions and care-provider practices in the hardest-hit countries. In Kenya, the simple fact that 270,000 patients have been put on antiretrovirals in just a few years illustrates the pace and scope of the changes – especially since management of chronic diseases was until then a relatively small part of Kenya's public healthcare sector.

In July 2010, results from Kenya's latest national HIV prevalence survey were just beginning to circulate. The United Nations held Kenya up as an example, because the HIV prevalence in young adults aged 15 to 24 had declined between 2007 and 2010, meeting the goals set by the donor States. The UN's announcement of these encouraging results implied that Kenya was at the cutting edge of the fight against the pandemic. In an international context where the will of donors is flagging, clearly it was useful to show – using the example that a part of Kenya's youth were adhering to preventive measures – that the worldwide campaign against HIV could indeed claim some victories.

Repeated requests made by the Campaign for Access to Essential Medicines to the teams in Kenya for an example of how reduced funding impacts patients in the field are further evidence that global strategy affects local reality. Actually, Kenya has not yet lacked funds – in fact, it is having trouble using the money that's available and justifying the use of certain sums already spent. "Kenya's three Round 2 grants have reached the end of their 5-year terms, with a total of 47% ($67 m.) of the agreed Phase 1+2 funding un-disbursed and no longer available….Audits at the end of 2004, 18 months into the Round 2 grants, showed that 99% of the $7 million disbursed by then was unaccounted for. In August 2008, the Global Fund still listed those audit queries as being unanswered."[16] Kenya is neither ahead nor behind in the battle against the pandemic, but simply in a place of its own, which cannot be reduced to a single point on a numeric scale of quantitative indicators for monitoring the global HIV strategy. When pressed, the Kenya teams managed to make their point of view known to Access Campaign headquarters, and released a public statement limited to the country but in relation to the facts. At the same time, MSF communications departments everywhere else rallied to condemn the donor states' lack of mobilisation at the XVIII International AIDS Conference, organized by the International AIDS Society, in Vienna in July 2010. How were public health institutions, only recently described as extremely inadequate, supposed to absorb all that money without a hitch and transform it into quality care?

The non-use of some of the international funds allocated to fighting HIV in Kenya was a reminder of a reality that didn't tally with MSF advocacy, and thus had to be avoided in general discourse aimed at describing the weaknesses in the global pandemic response. First, information slanted in this way is objectionable, because it reduces a complex

16. Bernard Rivers, Aidspan, *Problems with Kenya's Global Fund Grants.* This paper was presented at a retreat of the Kenya Country Coordinating Mechanism meeting, Naivasha, Feb. 19-21, 2009, pp. 1-2.

problem to the single issue of whether foreign institutions in the country in question have "the political will to fund the fight against HIV." While the reductive nature of the message has been brought up, it is still considered useful to the cause. Repeated often enough, these buzz words take on the appearance of truth – based upon which decisions are made and errors committed. Practitioners, however, know that healthcare is not made by money alone, and that new scientific knowledge and intense social and political mobilisation are critical to progress in public health.

UNDERSTANDING, AND BEING UNDERSTOOD BY PATIENTS

An anthropological study[17] was conducted from April to June 2010 to try to explain why some patients were receiving treatment too late, when their immune systems were already badly compromised (CD4 count below 100/mm3, WHO Clinical Stages 3 and 4).

The study also had several other aims: to explain how the "Luo community" viewed the HIV epidemic, to determine the epidemic's sociocultural impact, and to assess the elements of Luo culture that might favour HIV transmission. The study's sponsors, MSF operations managers at all levels (headquarters, capital of the country, and Homa Bay project), wanted to learn about patient perceptions and motivations in order to influence attitude and behaviour changes.

In order to explore the reasons why patients wait "too long" to come in, we need to define the "right time" to start HAART. According to promoters of HIV treatment,[18] ideally, all adults would be screened voluntarily once a year. If positive, the hope is that the patient would heed the instructions for preventing transmission of the disease to others, encourage those close to him to be tested, and start antiretroviral therapy "at the right time," that is, before his immune defences collapse. There are several problems with this ideal.

The "right time" invoked by care providers has changed constantly over the past few years. When we began prescribing HAART in 2001, treatment was rare and reserved for those who would now be considered "too late." The situation for some of the people who are now coming in "at the right time" is changing, since the CD4 threshold below which HAART must be prescribed has just been raised. Basically, patients are now being asked to come in sooner. While they are coming in "at the right time" now, they will soon be considered "late." The "right time" depends on both the state of medical knowledge and the ability of the healthcare services to provide treatment, and both of these are in constant flux. As a result, the criteria for starting HAART has changed frequently over time; from the initial period when drugs were scarce and the most serious cases given priority, to the current period of greater availability, where care providers want to start HAART earlier. Aside from its negative connotations, the definition of "patients who come

17. Vanja Kovacic, *Access for more – Overcome barriers to access to HIV/AIDS care in Homa Bay district, Kenya. Phase 1*, June 2010, Homa Bay, Kenya. A qualitative survey was conducted using in-depth interviews in the patients' own language. The fifty or so patients interviewed were adults from the Homa Bay and Ndhiwa districts who had been followed during the previous year at the Homa Bay district hospital's Clinic B (run by MSF). About thirty members of the patients' entourage likely to have an influence on their decision were also interviewed, including practitioners of traditional medicine, religious healers, herbalists, traditional birth attendants, religious leaders, members of the patients' families, and village chiefs.
18. *Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report 2009,* UNAIDS, UNICEF & WHO, Geneva, 2009. http://data.unaids.org /pub/Report/2009/20 090930_tuapr_2009_ en.pdf.

in late" is not sufficiently stable to prevent confusion. In 2010, French health officials estimated that a third of HIV patients came in "too late." Even with its considerable resources, one of the world's best healthcare systems cannot produce patients disciplined enough to come in exactly on time. In comparison, in the first quarter of 2010,[19] 56% of treatments in Homa Bay were started at "the right time," that is, on patients who were at WHO Clinical Stages 1 and 2.

Clinical staging of new HIV patients

	N	Proportion (%)
Stage 1	152	30
Stage 2	133	26
Stage 3	192	38
Stage 4	33	6
Total	510	100

We should note – by way of reference regarding the limits of qualitative studies – the conclusions of a study[20] conducted in France investigating the reasons for participation and non-participation in cancer screening: "[translation] There are a number of types of justification and explanation that shed light on the choice to have, or not have, screening tests: the person's relationship to health and their body, their opinion regarding the principle of prevention, the fact of having been affected by cancer, their trust in their doctor, the fear of knowing, the fact of having receiving an "invitation letter" from the anti-cancer organisation, etc. But the way in which individuals relate or position themselves with regard to these explanatory factors is always singular. And it is always this specific relationship that explains why individuals act or not, take up the prevention system, or not."

It would be more appropriate for us to ask ourselves about the problems arising from the patient/care-provider relationship, without prejudging about who is early and who is late. To describe patient attitudes regarding available care, we can use an economic and sociological classification scheme[21] from a study on the non-use of social assistance by eligible individuals. This classification distinguishes three typical situations: individuals who are not aware that assistance exists or that they are eligible for it (not aware); individuals who are aware of the assistance but choose not to ask for it (not requested), and individuals who have requested the service, but haven't received it (not received). An examination of the data from the anthropological study in Homa Bay suggests that the reasons for non-use of HIV care often fall into the "not received" category. Prompted by their symptoms, all patients had gone to see either public health service representatives

19. Quarterly report on medical activities – Kenya Programmes First quarter 2010: January – March.
20. Pierre Mazet, *Motifs de participation et de non participation au dépistage du cancer. Enquête qualitative auprès des habitants de deux territoires de l'agglomération grenobloise*, Étude n°33, Grenoble, Odenore, Dec. 2009.
21. Observatoire des Non-Recours aux Droits et Services http://odenore.msh-alpes.fr/documents/WP1definition_typologies_non_recours.pdf.

(60%) or other practitioners (40%), the latter most often outside biomedicine. This doesn't mean that "not requested" had no part in the non-use of care. But the fact is that all patients tried to consult. Neither of the two healthcare sectors – biomedical or non-biomedical – offered patients appropriate diagnosis and treatment in a reasonable amount of time, despite the prevalence of the disease and the severity of their condition. Looking at the care trajectory of the fifty or so patients studied, only half of the patients were diagnosed by their fourth visit, in a region where 20% of adults are infected. Just over one in ten patients had to make seven attempts before being diagnosed and started on treatment.

The anthropological study also looked at the relationship between Luo culture and HIV transmission. The Head of Mission practicing there between 2003 and 2007 had already broached the issue in her report: "Luos, an exception among Kenyan tribes, don't circumcise, they are also polygamous (60% of families in Rusinga highland in 2001). These two HIV transmission factors combine with others such as the consequences of the ongoing women inheritance culture, a culture of early sexual relationships before marriage (traditionally tolerated in elopement and a behaviour currently accepted by the majority of Luo men) in addition to prostitution caused by modern life and poverty (young widows refusing to be inherited or unmarried young women seeking a livelihood). Prostitution is especially common along the lakeshore where young fishermen benefit from a regular income. These factors have made the local Luo society highly vulnerable to sexually transmissible diseases. This accumulation of risk factors explains why HIV prevalence is up to 40% among adults in some areas of Nyanza."

Tribal membership and identity continue to have considerable importance in the social and political life of contemporary Kenya. Until the most recent elections, many Luo didn't recognise themselves in the country's government. Homa Bay is a majority Luo region, where HIV prevalence is three times the national average. In this context, the natural tendency of those fighting HIV is to claim a link between the severity of infection in this region and what they consider the relevant sexual practices in Luo culture. Two of these practices, one of them levirate marriage (where a man must marry his brother's widow), are mentioned by AIDS actors as favouring transmission of the virus. Both are connected with resumption of sexual relations by a widow, or her remarriage. While there may be a particular link between Luo culture and virus transmission, simply blaming certain aspects of the tradition governing sexual activities in widowhood is not a convincing argument. Culturalism is not the only explanation of why Luo culture is being blamed. There is also a widespread belief within AIDS organizations that gender inequality contributes to virus transmission. Epidemiological data on HIV prevalence by gender in Kenya confirms the view that women are at a disadvantage in negotiating sex and its attendant particulars (e.g., condom use). But there is nothing to indicate that if widows resumed sexual activity

outside the rules of Luo culture they would be less likely to transmit the virus. The HIV epidemic can sometimes seem like a boon to those who would like to change tribal traditions and gender relations. Indeed, it's hard for activists to resist the temptation to justify a "modernizing" or feminist position by claiming that it's better for health.

Freed from the assumptions about patient "lateness" and the harmful health effects of Luo culture and gender relations, MSF's anthropological efforts could examine the patient-care provider relationship in greater depth by drawing on the already-plentiful literature and data from Homa Bay. The goal is to identify the parameters that determine the success of lifelong treatment of a disease that is fatal if treatment is interrupted or ineffective. Note that the literature review should not be limited to the AIDS literature, but should also cover medical specialties in which monitoring chronic patients is part of everyday practice.

Patients' experiences with the disease and its treatment are changing. In the late 1990s, patients starting HAART experienced long periods of painful and disabling symptoms. They were aware of being close to death, and had often accompanied a loved one during the terminal phase of the illness. In the initial phase of treatment, patients experienced relief from their symptoms and a return to normality.

Now, in Kenya as elsewhere, thanks to medical progress, the majority of patients are offered HAART based on lab tests, at a point when they have only minor clinical signs of the disease, or none at all. Increasingly, patients are being asked to follow a treatment protocol not to reduce pain and restore their independence, but to satisfy the abstract notion that if they do not correct an abnormal lab result, they risk suffering from the effects of a disease – AIDS – at some time in the future and which might kill them a few years down the road.

Moreover, the first patients received innovative, specialized care by care-provider teams inspired by a pioneering spirit conducive to an empathetic approach to the patient. Patient education was afforded considerable importance in those pilot programmes, combining a warm welcome, medical information, and enjoinders to follow treatment protocols carefully. This patient education explains, in large part, why care-provider teams in Africa achieved compliance and survival results on a par with those in more privileged environments (North America and western Europe, for example) with many more resources. Indeed, HAART's success is not simply that of a drug cocktail, but also of a medical practice that takes the time to explain the treatment process to the patient, encourages him to ask questions, and verifies, through this exchange, that the patient and someone close to him have truly grasped the concepts essential to the success of the treatment protocol.

Extending treatment meant involving personnel from health ministries with fewer resources than the organizations that had launched the first pilot projects. Patient education has been one of the first victims of this personnel shortage, even though, due to the changing patient profile, it is now more essential to success than ever. We should note that in Kenya, the word used in both society and healthcare institutions to designate patients is "clients." During a visit to a clinic taking part in the decentralization of treatment from the district hospital to peripheral health centres, a remark by the foreign visitor to a Kenyan colleague – "Here, this is not HIV friendly" – prompted an unequivocal response: "Kenya is not client friendly." Yet one of the main issues in chronic disease management is avoiding disruptions in the continuity of care.

Why would a patient remain loyal to a practitioner who bullies him? Observing consultations outside the district hospital's Clinic B, in peripheral care centres (e.g., Marindi, Ndhiwa and Rangwe) helps to see what discourage patients. Waiting times are long. Forget confidentiality – there is no guarantee of even minimal discretion, and patient files are easily accessible. The visit is basically just a set of administrative acts, during which other members of staff frequently open the door to the examination room for one reason or another. Patients rarely receive a physical exam, and there is as little time for discussion as there is staff training to provide pertinent information. Patient interviews conducted at the MSF-run clinic (the district hospital's Clinic B), on the other hand, emphasized the importance of courtesy, discretion and patient education.

The anthropological study showed that patients did not receive care when they requested it. It also showed that the reasons for not requesting care, aside from the fear of death, were the fear of loss of reputation and of treatment side effects. How, then, will the even worse consultation conditions in a decentralized system help reassure patients? MSF, upon whom this point has not been lost, is trying to support peripheral health centre teams, using a mobile team (clinician, nurse and counsellor) to improve patient care. While this support is useful, its impact is limited by existing constraints – in particular, the instability of MoH staff and the lack of suitable facilities.

The lack of dedicated space shows the extent to which chronic disease management has never been an important objective in the countries where MSF works. A good illustration of the relationship between treatment objective and architecture is Malawi's Chiradzulu district hospital. The layout of the new European Union-funded district hospital, opened in 2005, makes no provision for HIV/AIDS activities, despite the fact that nearly one in five adults in the district are HIV-positive, and 30,000 HIV patients are now being treated there. Some of the HIV activities in the Chiradzulu hospital are conducted in rooms intended for trauma care. The Homa Bay district hospital needed new buildings to be able to provide HIV and TB care.

Many of the patients are poor farmers whose financial problems are exacerbated by their illness, as their income and borrowing ability decline and expenses rise. Patients are not asked to help pay for antiretroviral drugs, consultations, or some lab tests. But that doesn't mean they don't have to pay anything – there are still transportation costs and bills for lab tests and medications not included in the "free" care.

There is yet another complicating factor. While it is true that a large percentage of patients are now started on treatment before their immune systems become too damaged, this doesn't mean there are no more complicated cases requiring specialized medical care. If clinicians fail to respond to requests for medical help when the disease worsens because of the complexity and cost of care, this can't help but impact treatment adherence and patient loyalty. Why trust practitioners who abandon "clients" just when their condition has deteriorated to the point where care is critical to their short-term survival? Abandoning terminal patients to deprivation (food, hygiene and treatment), pain, and isolation after their years of loyalty to the care system can only make those who follow even more reluctant to follow medical recommendations. Another constraint for care services is to be able to contact patients at home when they stop coming in for appointments. The need to extend care beyond the walls of healthcare facilities is also an issue in the management of terminal patients who are no longer mobile. Extending the care delivery network beyond the institution is essential to finding patients who have stopped coming in. Already, monitoring of patients over several years shows a disquieting percentage "lost to follow-up". Of the 510 new patients at the district hospital in the first quarter of 2010, 494 were lost to follow-up.

New patients and outcomes during the first quarter 2010 – Homa Bay programme

	N
New patients total	510
New starting HAART	346
Deaths	14
Lost to follow-up	494
Transfer out	139

These data are consistent with data collected in other settings:[22]

"[translation] Recent epidemiological studies describe the default, treatment failure, and viral resistance rates faced by treatment programmes in Africa:

• In many countries, a high percentage of patients stop their ART early (25% of patients stopped after 12 months, and 33% stopped after 24 months) (1).

• These interruptions are due, in part, to early patient death – deaths related to delayed diagnosis of HIV infection – but also, in almost half of cases, to the patient discontinuing all medical follow-up.

• A study of five African countries (Botswana, Malawi, Uganda, South Africa and Cameroon) found that 15 to 25% of patients were in virological failure after 12 months or more of treatment (2).

• A study conducted in Cameroon reported that 16.9% of patients showed viral resistance after 2 years of treatment (3); a broader study showed that nearly 90% of patients in virological failure were carrying viruses resistant to at least one of the three classes of antiretroviral drugs (4).

These high early default, therapeutic failure and viral resistance rates reflect the current shortcomings and limits of care and treatment mechanisms. Treatment defaults are extremely damaging to both the individual (increased morbidity, early death) and the community (in particular, by favouring the emergence and spread of viral resistance). They increase costs – the money spent actively searching for these patients, and then for their subsequent medical care – especially since the second-line treatments needed for patients with resistant viruses currently cost $1,200 per person per year (eighteen times more than the initial treatment). The number of people who need second-line treatment is already very high."

1. Tassie J-M, Baijal P, Vitoria MA, Alisalad A, Crowley SP, Souteyrand Y. Trends in retention on antiretroviral therapy in national programmes in low-income and middle-income countries. *J. Acquir Immune Defic Syndr.* 2010; in press.

2. Harries A, Zachariah R, van Oosterhout J, Reid S, Hosseinipour M, Arendt V, et al. Diagnosis and management of antiretroviral-therapy failure in resource limited settings in sub-Saharan Africa: challenges and perspectives. *Lancet Infect Dis.* 2010; 10 (1): 60–65.

3. Kouanfack C, Montavon C, Laurent C, Aghokeng A, Kenfack A, Bourgeois A, et al. Low levels of antiretroviral-resistant HIV infection in a routine clinic in Cameroon that uses the World Health Organization (WHO) public health approach to monitor antiretroviral treatment and adequacy with the WHO recommendation for second-line treatment. *Clin Infect Dis.* 2009; 48 (9): 1318–22.

4. Gupta R, Hill A, Sawyer A, Cozzi-Lepri A, von Wyl V, Yerly S, et al. Virological monitoring and resistance to first-line highly active antiretroviral therapy in adults infected with HIV-1 treated under WHO guidelines: a systematic review and meta-analysis. *Lancet Infect Dis.* 2009; 9 (7): 409–417.

Even leaving aside issues related to drug efficacy and side effects, a quick glance at the conditions that help to establish the relationship needed for successful treatment indicates that such conditions are far from the reality at public institutions. Kenya has started 270,000 people on treatment in just the past few years, and there are hundreds of

thousands more waiting. It is plain that public healthcare services are being given a task that they cannot accomplish in high-prevalence regions. This means that other care-delivery models are needed. This tension between the lack of available care and the number of people waiting for treatment has existed since 1996 and the response has primarily been a combined approach that is both economic (lowering prices and increasing public funding) and medical (offering empathy and medical advice, simplifying the treatment protocols, and applying the subsidiarity principle[23] when choosing personnel). There is still room for further reducing the patient's share of the costs. Avenues for improving treatment efficacy, reducing side effects, and simplifying storage and dosing are being explored. HIV and immune status (CD4 count) can already be assessed by rapid tests; the same will soon be true for viral load. To sum up, the limits to expanding and adjusting available care are related primarily to the state of public healthcare facilities.

MSF'S ROLE

DISCOUNTING MSF'S HISTORY AND THE ILLUSION OF POWER

The draft report from the July 2010 *mise à plat* (MAP)[24] on the Kenya projects (see Appendices), written in telegraphic style to allow rapid distribution to the field, summed up a decade-long policy: "Late 90's – refusal to get involved and nothing to offer. Early 2000s –involvement and significant early successes (treatment and advocacy)".

It is a common misconception that the Association's involvement in HIV began with HAART's arrival in the field in the early 2000s. In the minds of many colleagues, the three decades of rapid progress described earlier are reduced to only one – the last. In reality, the number of HIV projects prior to the 1997 arrival of HAART was already on the same order of magnitude as today. MSF teams were actively working in the main epidemic foci in Africa (western, eastern and central) and Asia, seeing patients, distributing information about the disease and how it is spread, preventing transmission during medical and nursing procedures, fighting for access to care, and treating opportunistic infections. Before the late 90s, the possibility of stopping the virus from multiplying in the body was virtually nonexistent, and the immune system's decline irreversible. Hope at that time rested on prevention campaigns, which to many meant encouraging people to change their sexual behaviour. Those who had doubts about widespread change in sexual behaviour or whether it was appropriate for MSF – a foreign humanitarian organization – to participate in such campaigns were seen by their detractors as refusing to get involved in the fight

23. According to the subsidiarity principle, people at a higher level should refrain from doing what someone at a lower level can do.
24. The *MAP* is a meeting held twice a years, at which the managers from a given country and headquarters get together to examine the results and define the objectives for field programmes.

against AIDS. These controversies and the Association's limited participation in the public debate over how to fight HIV is remembered in the collective conscience of its members as an absence, or even a refusal to mobilize. In contrast, the early 2000s is seen as a period of heroic engagement with a series of rapid changes leading to the use of HAART in MSF-supported projects.

At meetings in Kenya with representatives from other institutions, MSF is given little credit for having been among the first to use and demonstrate the effectiveness of a protocol that now allows millions of patients to be treated. The initiative of which MSF is most proud – having been the first to prescribe antiretrovirals, at no cost to patients, in a public hospital in Kenya – has been forgotten. On the other hand, our Association is admired – even feared – for the weight its words carry in the public debate. While MSF's mobilization against HIV is often described as belated, the impact of its advocacy campaigns on decisions by multinational pharmaceutical firms, the World Health Organisation (WHO), and donor countries is overestimated. Governments have been committed to fighting infectious diseases for as long as there have been state institutions, because epidemics threaten their ability to ensure public safety, and have significant economic consequences. The primary goal of governments, however, is not to provide care to individuals, but to ensure public safety and avoid economic losses and political instability.

In modern times, the exemplary model for fighting infectious diseases is the campaign to eradicate smallpox: an initial investment (the vaccination campaign) and a decisive result (eradication of the disease). The strategy is to eliminate the cause (the disease), not manage its consequences (the patients). How, then, to explain that, in the case of AIDS, donor states have agreed to spend several billion euros a year on treating patients with no prospects for eradicating the disease? The threat to public safety and the ubiquity of HIV, an extraordinary level of social mobilization, the potential major economic repercussions, rapid scientific progress and countless other factors have helped make AIDS – and the responses to it – unique. But to understand why donor states have found it in their interest to depart from their usual position and get involved in treating millions of patients without any prospect for ending the disease, we have to look at the impact that the public debate on pharmaceutical intellectual property issues has had on political decision-making.

In the late 1990s, when extending the use of antiretrovirals beyond high-income countries became an issue, one of the main themes of World Trade Organization (WTO) efforts was the globalization of intellectual property rules applying to trade. The high price of certain drugs – like antiretrovirals in the late 1990s – can be explained, in large part, by the trade monopoly conferred on pharmaceutical firms by patents. The combination of a public health disaster and prohibitive drug prices disproportionate to the costs of

production raises the question of whether intellectual property rules are compatible with public safety – in this case public health. This was a major challenge. In today's world, wealth and power are less often derived from ownership of physical objects, and increasingly based on intangible ownership of the knowledge (legally formalized by patents) that allows the production of objects and services. Reducing the economic advantages conferred by patents means reducing the value of that portion of capital represented by intangible objects.

The too high price of AIDS drugs in the late 1990s – several thousand dollars per patient per year – created friction between two political objectives: private ownership and public safety. The moral dimension of the conflict added a dramatic effect, enhancing its public visibility. The tension between the two imperatives – private ownership and public safety – exposed the fragility of an economic system that relies, in large part, on the belief that ownership of knowledge essential to public health can remain in the hands of a small number of individuals and institutions for long periods without any significant conflict. The major economic powers urgently needed to offer a series of concessions on access to drugs, before the "our lives versus your profits" debate compromised their ability to extend intellectual property rules to all global trade – especially since, at the time this was happening, in 2001, negotiations on other WTO issues were deadlocked and the institution was weakened. In that particular context, the major economic powers, led by the United States, supported a softening of the intellectual property rules – for the pharmaceutical market only – vis-à-vis public health institutions.

Basically, the fight against AIDS benefitted from an extraordinary combination of economic and political circumstances. Circumstances so conducive to rapid change in public health policy cannot last forever, nor be reproduced at will through advocacy. When they do occur, however, they create political openings and offer those capable of seizing it an opportunity to change long-established power relationships.

MSF AND DEVELOPMENT POLICIES

After the crisis caused by the lack of antiretrovirals in the countries hardest hit by HIV was resolved, the question of how and for how long MSF should be involved in the fight against HIV became the focus of internal debate once again. Questions about involvement in so-called "development" activities have been debated since the Association's very first General Assembly, in 1972: "[translation] There are two opposing lines of thought: the first calls for volunteer medical aid that can be mobilized rapidly for short missions […]. The second, supported by volunteers returning from Bangladesh and Upper Volta, argues for the other urgency – the chronic lack of medical care in the Third World".[25] Nearly forty years later, the debate continues in the report from the June 2010 Kenya MAP, which refers to health development-type involvement, whose pertinence is questioned: "[translation]

25. Anne Vallaeys, *Médecins Sans Frontières: La biographie,* Paris, Fayard, 2004.

Mid-2000s, starting to question the pertinence of projects shared by field and headquarters, the latter also being concerned with the cost of the projects and the fact that they might not be consistent with MSF's role." Similarly, in late 2008, the Operations Department[26] in Paris considered transferring a large portion of HIV activities, in Kenya and elsewhere, to other organizations: "[translation] This effort should start with an examination of our international, national and local work environments, to identify possibilities for transferring the responsibility for care and supplying drugs to some portion of the 'stable' patients that we are now treating directly to other actors (NGOs, Ministries of Health, peer groups, etc.)."

To better understand the changing opinions on "development" policies within MSF, we need to recall the state of international relations at the end of WWII. The Cold War had been intensifying since the late 1940s, and the so-called "underdeveloped" countries were the focus of a struggle for influence between the two sides. Contributing to the development of poor countries was one of the four points of President Harry S. Truman's 1949 inaugural address:[27] "We must embark on a bold new programme for making the benefits of our scientific advances and industrial progress available for the improvement and growth of underdeveloped areas. More than half the people of the world are living in conditions approaching misery. Their food is inadequate. They are victims of disease. Their economic life is primitive and stagnant. Their poverty is a handicap and a threat both to them and to more prosperous areas." In the early 1950s, French demographer Alfred Sauvy coined the expression "Third World" in reference to the Third Estate – under the French *Ancien Régime*, the voters (and their representatives) who did not belong to either the nobility or the clergy. In reality, the goal of developing the third part of the world – the one outside of NATO and the Warsaw Pact – transcended many political divisions, as did, in other times, Christianisation or the concept of the civilizing mission of colonization.[28] The dominant ideology of the time held that science, industrialization and economic growth would soon allow "backward" nations to close the gap, provided the "advanced" nations supported the project by allocating funds, adopting new trade rules, sharing scientific knowledge, and transferring technology.

It was in this context that a group of Third World nations launched the Non-Aligned Movement, introduced at the Bandung Conference (1955) and the Belgrade Conference (1961) as an alternative to the declining colonial powers and U.S. and Soviet hegemony. The membership of Cuba, North Vietnam, Yugoslavia and the Republic of China, however, was an indication that the Non-Aligned Movement would be unable to completely escape confrontations between the two opposing economic and political systems.

Traces of these typical Cold War confrontations can be found in internal discussions and MSF publications on the direction of international development aid. Third-worldism,

26. *Politique Opérationnelle 2009-2011. Bilan et perspectives 2008-2009,* Centre Opérationnel Paris.

27. http://www.trumanlibrary.org/calendar/viewpapers.php?pid=1030

28. It should be stressed that outside of this international consensus there were currents of thought opposed to these "civilizing" enterprises on both the right and the left, though obviously they employed different lines of argument.

development, poor nations' debt, famines, and international health issues are at the heart of a colloquium conducted by the *Liberté Sans Frontières* foundation, an MSF satellite from 1982 to 1989. In 1986, as part of that discussion, MSF President Rony Brauman wrote: "[translation] The main demands of the "new order"[29] desired by the entire third-worldist movement have this in common: they pursue perfectly laudable goals using methods that will inevitably destroy them."[30]   Brauman specified two important points. First, the critique "came from within the third-worldist movement itself." Second, it was aimed primarily at a "leftist" idea of development that he considered dominant in France, while "the right" was nowhere to be seen. In LSF's view, third-worldism – the love child of "Leninism and Christian socialism" – represented "a kind of extension of traditional social morality on an international scale." By the late 1980s, development had become an inalienable human right, thus taking on an aura of complete unreality: "The right to development is an inalienable human right by virtue of which every human being and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realized."[31]

LSF's public positions were defined in opposition to third-worldism's then-considerable influence in the health domain. The International Conference on Primary Healthcare was held in the USSR, in the town of Alma-Ata, Kazakhstan in 1978. Its final declaration accorded an important role to community health workers, modelled on Maoist China's "barefoot doctors."

29. In 1974, the UN General Assembly adopted the *Declaration on the Establishment of a New International Economic Order (NIEO)*; one of its objectives was to respond to development issues related to the price of raw materials.

30. *Le Tiers-mondisme en question.* Rony Brauman (ed.), Paris, Olivier Orban, 1986.

31. United Nations General Assembly Resolution 41/128, Dec. 4, 1986.

32. *Populations in danger,* François Jean (ed.), London, John Libbey & Co., 1992.

LSF's hostility to communist-influenced health policies wasn't based solely on a rejection of the deadly, freedom-killing attempts at social and public health engineering, which it saw as the death throes of a totalitarian thought process whose sentimentalist third-worldist tone failed to mask its dangers. The rejection of totalitarianism was, in fact, reinforced by experience in the field. It was operations to assist Third World refugees during MSF's first twenty years that had the greatest impact on the Association's political and technical choices. These refugees were Vietnamese, Cambodian, Laotian, Afghan, and Ethiopian, proving, "by their very existence, the failure of communism". Third World "popular democracies" were producing nearly 90% of the world's refugees.[32] In the 1980s, however, while MSF was formulating its criticisms of state authoritarianism, the neoliberalism of Ronald Reagan and Margaret Thatcher was winning to such an extent that it became a threat to public health in poor countries, and to all socially progressive public policy. The structural adjustment policy imposed by the international financial institutions was leading to significant budget cuts in "developing" countries, while the Cold War was on the wane. In reality, LSF did not take into account this shift in international power relations when it opposed third-worldism.

The fact remains, however, that at the same time it was positioning itself in opposition to third-worldism, MSF was participating in long-term third-worldist-inspired public health development activities within broad coalitions of actors (states, international organizations, and NGOs). While this was true of the French section, the first in the Sans Frontières movement, it is even more obvious in the history of the Belgian, Swiss, Dutch and Spanish sections, which until the early 1990s were involved primarily in public health development projects.[33] This is evidenced by the fact that both in practice, through its field interventions, and by its public positions, MSF has supported every new, major international health initiative: the Expanded Programme on Immunization (1974); the promotion of primary healthcare following the Alma-Ata (1978) and Bamako (1987) conferences; the health-related Millennium Development Goals (2000), and the goals of the Global Fund to Fight AIDS, Tuberculosis and Malaria (2002).

From the earliest editions of MSF's *Clinical Guidelines*,[34] the introduction places the Association's medical action squarely in line with the movement for universal primary healthcare launched at Alma-Ata. "[translation] Curative care is only one component of the healthcare programmes adapted to the needs of developing countries. It is important to remember that other priority programmes also need to be developed. These are the foundation of all action aimed at improving the health status of a community. These high priority programmes focus on nutrition, water, hygiene, sanitation, the expanded programme on immunization and mother-child health." Admittedly, MSF did criticise the final Alma-Ata Declaration to some extent. The first had to do with the definition of "Health for all by the year 2000," which seemed completely unrealistic: "The Conference strongly reaffirms that health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector." The second criticism was aimed at the role to be played by community health workers in promoting primary healthcare. The magnitude of the responsibilities entrusted to a category of personnel with no medical or allied healthcare skills did not bode well for success, especially since the training, supervision and material resources to support their activities were lacking. That didn't, however, stop the Association from distributing David Werner's handbook, *Where There is No Doctor* – the veritable medical bible for community health workers – to every MSF field project library, where it remained until the mid-1990s.

In 1992, the Association's internal debate over participation in development policies went to a new level. In 1985, the opinion of LSF members was expressed in the conclusion of the *Third-worldism in question colloquium*: "[translation] Third-worldism is an obstacle to development." By the early 1990s, the problem was no longer third-worldism, but

33. Éric Goemaere, "Une ONG au ministère", in *Utopies Sanitaires,* Rony Brauman (dir.), Paris, Le Pommier, 2000.
34. Médecins Sans Frontières, *Clinical Guidelines*, Paris, Hatier, 1988.

development itself. In the foreword to the first collection[35] written since the suspension of Fondation Liberté Sans Frontières in 1989, Rony Brauman, then MSF International Council president, proposed a new definition of humanitarian action: "First, let us hazard a minimum definition. Humanitarian action aims to preserve life and human dignity and to restore people's ability to choose. To accept such a definition is to say that, in contrast to other areas of international solidarity, humanitarian aid does not aim to transform society but to help its members get through a crisis period, in other words when there has been a break with a previous balance." What this new definition did was free humanitarian action from the obligation to participate in a global enterprise to transform the world, where the combined benefits of science and economic growth would ensure that "underdeveloped" countries could catch up, provided they followed the recommendations of "more advanced" countries. For humanitarian medicine – whose origins are, in part, linked to historic experiments (colonial military medicine, missionary and social reform medicine) in the march toward a new world – the impact of this break was considerable. It could now distance itself from a humanitarian action that might contribute to universalizing the civilization process begun in Europe and gradually spread to the rest of the world.

The influence on MSF members of this updated definition of humanitarian action by Rony Brauman in 1992 explains why the wording to the effect that the Association intends to respond to crises, on an emergency basis if possible, crops up again and again in the internal debate. "At the end of the 1990s, Médecins Sans Frontières (MSF) got involved in HIV/AIDS because we viewed it as an emergency: today, MSF still believes this is a crisis requiring an exceptional response."[36] Similarly, the June 2010 Kenya MAP report says, "2009, recommitment to MSF's role in the fight against HIV, which is again seen as an emergency…." But what should be our attitude in response to crises whose resolution involves long-term participation in a process of social transformation, like setting up better infectious disease monitoring, for example? AIDS projects and Access Campaign advocacy are examples of where we go beyond Rony Brauman's 1992 definition. AIDS is a crisis that has already lasted several decades, and the introduction of HAART in poor countries is an obvious social transformation. While Brauman's definition might free humanitarian action from the constraints of belief in the ineluctable march of progress guided by law and driven by the combined effects of science and economics, it can also preclude potential engagements by explaining that humanitarian aid "does not aim to transform society but to help its members get through a crisis period, in other words when there has been a break with a previous balance." But is it possible to help a population get through a crisis while choosing not to participate in transforming the society in which the crisis occurs?

In MSF's internal debates, the position that claims to give priority to the incontestable "save lives here and now" is offering an *argumentum ad verecundiam*. It expresses fidelity to the supposed origins of the Association, though in fact there is no evidence that there was

35. *Populations in danger,* François Jean (ed.), London, John Libbey & Co., 1992.
36. *No Time To Quit: HIV/AIDS Treatment Gap Widening in Africa*, MSF, May 2010. http://www.msf.fr/drive/69bcb2a7e6c55b47888bd5f5204ce6fc.pdf.

ever a clear-cut decision, but on the contrary, evidence of a contradictory discussion that began at the first MSF General Assembly, and continues to this day. Emergency response is often held up – wrongly, as history proves – as the activity to which we must always remain loyal. The contradiction between the claim that MSF did not originally participate in development activities and the facts is partially hidden from the collective imagination, thanks to the organization's promotional communications, which tend to emphasize the image of a humanitarian medical organization heroically responding to emergencies, above the political fray. The debate is reduced to an ontological argument, thus avoiding the political dilemmas. The hardening of identity in the arguments of those who are now against involvement in so-called health development activities is no minor detail to their opponents, who appear to disagree with them to the point of no longer being considered to possess the "MSF identity." They aren't just dissidents – they're outsiders to the association they joined. A Kenya team leader who came out in favour of joint health development projects with public institutions thought she heard a representative from headquarters reply that she "had the wrong organization."

Yet the discussion on the limits of MSF's role shouldn't end in a decisive victory by one side or another. MSF isn't a Red Cross satellite or a UN agency, and it certainly isn't the appointed operator of some former colonial power's international cooperation department. The association defines for itself the scope of its mandate, offering its members the freedom to explore limits while giving meaning to their volunteer service, transforming it into something more than just a form of daily self-sacrifice. The authors of the MSF Charter used the expression "populations in distress"; twenty years on, Rony Brauman spoke of "populations in crisis." These expressions can be thought of as malleable, or able to convey multiple meanings. They are inclusive – sometimes too inclusive – and ongoing critical reflection becomes essential. In this sense, the definition adopted in 1992 was a salutary attempt to narrow the range of possible meanings. But MSF's history (its relief operations, its position among aid organizations, and its institutional growth) also demonstrates how having a flexible definition of its role has been extremely productive. The goal is not to settle the debate, but rather to keep it alive, so we can take advantage of the flexibility of the expressions "populations in distress" and "populations in crisis." Internally, hardened identity references can only stifle critical debate. Definitively ending the debate over how to define the scope and methods of humanitarian action would narrow a priori the field of intervention. MSF would thus be depriving itself of the freedom to respond, other than with dogmatic pronouncements, to new and constructive questions by the teams at work in unique and changing fields of action.

BENEVOLENT AND SUSTAINABLE PUBLIC INSTITUTIONS?

The internal debate is not simply a discussion on the validity of MSF's participation in transnational public health initiatives. It is obvious to those who support this approach

that action necessarily involves the Association's participation in building public healthcare institutions. "As seen above, the need for integration of activities with the MoH to scale up treatment and progressively envisage coverage of ART needs has been clearly stated." This assertion is taken from the report written by the Head of Mission for Kenya from 2003 to 2007. Yet the idea that public healthcare institutions offer the most solid guarantee for sustainable public health action is debatable – not just politically, but also based on MSF's practical experience. Regarding AIDS, these same public institutions helped spread the virus (via injections, transfusions, etc.). Then they increasingly refused care as the disease became an everyday part of their clinical activities. And then, when an effective treatment (HAART) became available, the health ministries had enormous difficulty setting up administrative procedures for procuring it, although they could have obtained the drugs from the Global Fund without having to pay for them. Ten years on, few of these countries have made any financial effort to support HIV activities – and let's not even go into the misappropriation of international funds. The ambivalent (to say the least) view of the public health employees' integrity is illustrated by the pharmacy building constructed by MSF's Homa Bay team. The MSF AIDS project pharmacy was built on the Association's privately owned site, not in the compound of the district hospital where the project's medications are prescribed. Yet the building was constructed with a view to the long term, as its thermal insulation shows. The insulation was designed so that electric air conditioners would not be required to protect the drugs from high temperatures. The public sector is entrusted with the responsibility of covering the health needs of the population, but not to the extent of entrusting its employees with the keys to the pharmacy.

Whether to work in the public or private sector is a tactical choice, since neither offers a decisive advantage by its nature and in all situations. In Africa for example, church-affiliated healthcare centres often offer better quality, more reliable care than their public sector counterparts. In the Homa Bay district, a visit to the Catholic Asumbi Health Centre (35 inpatient beds, with ART and TB drug dispensing in addition to its standard preventive and curative activities) offered a good example of reliable, high quality care. In contrast, the history of public health institutions since the end of WWII in the countries where we work shows anything but stability. The history in African countries is a telling example: colonial medicine followed by independence and international cooperation (often with the former colonizer); collapse of public services in the 1980s, exacerbated by the structural adjustment policies of the international financial institutions; and then timid resumption in the late 1990s. This picture hardly suggests a clear relationship between the public nature of the healthcare institutions and the sustainability of steadily progressing healthcare activity.

PROJECT MANAGEMENT

During the visit, activities at Homa Bay were entering a new phase in their development: an increase and reinforcement of HAART dispensing sites outside the district hospital, in peripheral healthcare centres. This was the resumption of an effort to decentralize ARV dispensing initiated in 2003 in Ndhiwa. Paris headquarters, the capital team in Nairobi, and the field team all agreed on the direction to take. The latter was laid out, in broad strokes, taking both MSF objectives and local circumstances into consideration. The goal in Homa Bay – a high-prevalence area where available resources are insufficient – is to start treating as many patients and as early as possible. To achieve this, the plan is to increase the number of ARV dispensing sites in the Homa Bay and Ndhiwa districts, while ensuring that a large percentage of the patients being treated maintain the lowest possible viral load over time.

Despite the consensus on the objective, there was still some discomfort over how to concretely manage such an undertaking. The field team felt they were being asked for too detailed an action plan – the exact number of new dispensing sites in a given time period for a specific, detailed budget. The team pointed out that it could not provide that kind of planning data, because too little was known about the factors that would determine activities to construct a reliable timetable. To them, how to manage this new direction proposed by headquarters was just the first in a long list of hurdles to be overcome. Doing the project itself would be something of an adventure, since no one had ever done such a thing under social and epidemiological circumstances like those in Homa Bay. Moreover, it would mean maintaining high quality care for many years. The method usually used for monitoring projects seemed ill-suited to a totally new experience; due to their inherent risks, innovative enterprises require a special type of management. For example (and perhaps forcing the point slightly), it could be said that HIV care in district hospitals has become so familiar that this kind of project can be managed using a precise, pre-established plan. But overall, it's better to assume that each field project has social, cultural, economic and political circumstances unique enough to create uncertainty to justify a management that measures the work accomplished other than by merely looking at progress along a series of pre-defined steps.

MANAGING UNCERTAINTY

Basic research institutions and industry draw up management models appropriate to innovative projects, i.e., those with a high degree of uncertainty. By way of example, Bruno Latour's paper "*L'impossible métier de l'innovation technique* [The impossible job of technological innovation][37] provides a framework for monitoring these kinds of projects,

37. Bruno Latour, "L'impossible métier de l'innovation technique", in *Encyclopédie de l'innovation,* Philippe Mustar et Hervé Penan (ed.), Paris, Economica, 2003, pp. 9-26.

defined by the author as ever more costly experiments conducted by uncertain researchers and decision-makers who explore various degrees of uncertainty while capitalizing information, in the hopes of generating support for the proposed object among potential consumers and citizens. How, according to him, is such an undertaking managed?

"[translation] Calculations cannot be used to assess the chances of an even slightly radical innovation, because the world in which it will be introduced isn't stable enough to get reliable numbers; yet it would be futile to trust natural selection, since evolution isn't guided by any sense of efficiency. So do we just give up, extol the perils and greatness of research "that no one knows how to manage," and support random projects while hoping for the best? This approach – while it might be gratifying to researchers – usually ends up being a colossal waste. The issue is to know whether we can evaluate without calculations. Things that can't be calculated can still be described. But how do we give a good description of an innovation that doesn't yet exist? The way research projects are usually introduced makes evaluation nearly impossible. The researcher always tends to present his discovery as the eighth wonder of the world. Without flaws, opposition or competition, it shines – according to him – with the combined light of scientific truth, technical efficiency, economic profitability, and perhaps even social justice – not to mention the inevitable progress. To hear him, shareholders, venture capitalists, colleagues and consumers need only pull out their chequebooks. This is only human…but it isn't assessable.

Now let's suppose that someone asks the innovator to describe his project not as an absolute necessity, but as a perilous adventure that might well fail. We ask him to name the competitors whose products currently occupy the niche he wants to fill; we ask him to spell out the alternatives his project will have to settle for if it fails to convince; we want to know how it can be modified to incorporate opponents' objections, and so on. Instead of making his presentation watertight, we ask him to describe the risks. Why, you might ask, would that kind of description allow a better assessment than the impossible calculation? If we can't, in all fairness, ask the promoter of a radical innovation to calculate his project's chances, we certainly can't ask him to know the answers to all of these questions about the ecology of an innovation yet to come.

Nor does the evaluator's judgment apply to in-depth knowledge; to a nascent innovation we can only expect a nascent response. The evaluation is based not on a thorough knowledge of the project's environment, but only on the

increasing richness of the innovator's description. The inventor can't know the future; he might fail; he might be wrong; he is feeling his way in the dark; we can't rely on any expert to judge him; we can't trust unfair natural selection. While all of this is true, there is only one thing doesn't lie – Ariadne's thread remains solidly in our grasp – is the description of the project's future world richer and more detailed now, after the project has gone through testing, than when the innovator and evaluator last met? What the evaluator can measure with some small degree of certainty is the "learning delta", which makes it possible, between two tests or two meetings, to improve the description of the project, making it both more easily articulated and more negotiable. "Negotiable? Take it or leave it!" cries the indignant innovator. If that's the case, don't give him a penny – let the project languish on the shelf with all the other brilliant but unworkable inventions. What you're looking at is not the next great thing, but a white elephant, a labyrinthine contraption. In order to exist in ten or twenty years, the project has to be able to fit into an ecology as fragile as an Amazonian jungle; either the innovator tries to understand the environment with you, and you have to support him through his testing, or he's only interested in his project and not its ecology, and his project has no chance whatsoever of becoming reality. Demanding the description, you'll get savings the calculation wouldn't get you – and that beats counting on Darwin."

Along with the advice above – written for an audience from the world of industry – are sixteen indicators, divided into four categories. Each is aimed at preventing what the author calls "innovation pathologies":
  • the belief that an innovative project can be ballistic, in the sense that its initially defined trajectory will not change;
  • paranoia that manifests itself as hostility and contempt for any approach critical of the project;
  • manipulation so that the project is judged by unrepresentative experts and by non-relevant testing;
  • the lack of a plan, as signalled by the absence of any foreseeable object likely to reconcile the different environments and contradictory interests revealed by the early phases of the project.

Latour's indicators are presented briefly to underline the fact that there are specific methods for managing projects characterized by uncertainty in other professional environments – for example, basic research and industry. The stakes are not small, since – as the author points out – laxity has its price: "[translation] As one often hears at business

dinners, research and innovation are the surest (but definitely one of the most pleasant) ways to go broke." Given the risks inherent in innovation, the proposed management method consists of evaluating the "learning delta" measured from one step to the next as the project goes along. As each step is evaluated, resources are allocated to the project according to the knowledge and know-how acquired in the preceding steps. This way, allocated resources are transformed into new information about the different states of the world in which the innovation is deployed, and about the contours of the innovation-in-the-making that will have to find a place in it.

ADVOCATING BEHAVIOUR CHANGE: AN ADJUSTMENT VARIABLE FOR PUBLIC HEALTH POLICY?

The process of innovation in public health can be represented schematically using three variables:
- the state of science and technology;
- the political will;
- the required behavioural changes.

When scientific and technical knowledge exists but is inadequate (e.g., AIDS after HIV testing came on the market but before the discovery of the effectiveness of HAART), and political will emerges out of fear of widespread epidemics among heterosexuals (governments begin to view HIV as a threat to their security, economy, and political stability), then the demand for behavioural change is at its highest. Everyone on the planet is asked to restrict the number of their sexual partners and use a condom every time they have sex.

When the scientific and technical capital (e.g. development of HAART) and political will (resolutions by the G8 in 2000, and by the WTO and UN General Assembly in 2001) increase, the behavioural changes demanded are more moderate. HAART is introduced in the form of a twice-a-day tablet in poor and middle-income countries. The patient is not asked to help pay for the medication and is given information about the disease and his treatment. He then becomes subject to the constraints of managing a chronic disease, i.e., regular attendance at consultations and treatment adherence.

This suggests that the demands for behaviour modification required by the implementation of a public health policy increase in proportion to the need to compensate for inadequate scientific knowledge or lack of political will. This can be helpful when assessing the early potential of a public health proposal.

	1985-1996 : Use prevention to limit the spread of epidemics to broad populations	2000 : Treat patients with antiretrovirals in all countries	2010 : Reduce disease transmission through use of antiretrovirals and other methods
Science and technology	+	+++	+
Political will	++	+++	++
Behavioural change	+++	+	+++

How would we describe the current situation? Science is marking time. The prospect of a vaccine is becoming more remote, and the other preventive measures are unable to prevent the roughly two-and-a-half million new cases every year. No new antiretroviral drugs have come along to radically simplify treatment. The lab tests needed to follow patients are becoming more accessible, thanks to techniques that can be used in the resource-poor settings of our medical practice. A set of prevention measures and the widespread and ever-earlier use of antiretrovirals offer a glimmer of hope that HIV incidence, mortality rates, and ultimately, perhaps, prevalence, will decline. Donor states' political will is also marking time, as evidenced by the slower growth in HIV funding and assertion of other priorities, such as maternal and child health. Earlier we saw why treating patients without seeing their numbers decline was not part of the strategies deemed as pertinent by donor states. Yet the current officially-stated goal of governments and HIV coalitions is an ambitious one (universal access to treatment[38]), which would mean treating more patients.

In 2010, the desire for universal access to HIV treatment in spite of gaps in the science and the diminishing political will is creating a situation much like the one in 1985-1996. Back then, knowledge had advanced rapidly to the point where an HIV test and mono- and bitherapies were available, and the political will among donor states to respond to the epidemic was on the rise. Those who had relatively ineffective tools but who nevertheless hoped to stop the spread of HIV asked for maximal behaviour change – fewer sexual

38. Universal access to treatment is understood to mean coverage of at least 80% of HIV-positive patients with already damaged immune systems.

relations and partners, and systematic condom use. Today, scientific progress is slowing and the political will is weakening, as witnessed by the slower growth of available funds. The extremely ambitious goal of universal treatment means once again believing in the possibility of rapid, profound changes in the behaviour of patients, care providers, and healthcare institutions.

RADICALIZING THE FIGHT AGAINST HIV?

No treatment can completely eliminate the HIV virus in people who are already infected; thus, while success in providing universal access to treatment would lower mortality, transmission would still not be slowed enough to prevent a continuous increase in the number of carriers. This would mean having to solicit donors for more every year, with no prospect of putting an end to either the disease or the increase in costs. We showed above that the donors' commitment to treating millions of patients despite the lack of any prospect of eradicating the disease or reducing expenses was the result of a specific set of circumstances in the late 1990s. Today, the vast coalition of actors involved in social and political mobilization is expressing its concern about the weakening of government will.

In response, the "test and treat" strategy that promises to reduce transmission and costs in just a few years is gaining popularity. At the start of the Kenya visit, on arriving in Nairobi in July 2010, the goal of the first meeting was to decide whether MSF should sign an appeal by a coalition of Kenyan organizations entitled "HIV: eradication is within reach." The text called for a financial effort by foreign donors and the government in order to make Kenya an "HIV transmission-free zone." It also made reference to the position of authors from the two departments responsible for AIDS and tuberculosis at the WHO in favour of a test and treat-type strategy whose expected result would be the elimination of HIV epidemics. Some WHO experts expressed this position as individuals in an article in the *Lancet*.[39] In practical terms, they proposed testing everyone over the age of 15 every year, and starting everyone who tests positive on HAART, whether they have clinical signs of the disease or not. According to a case study by the authors – a mathematical model of a simplified South African situation (heterosexual transmission only) – there is reason to hope that the HIV prevalence could drop from 10% to 1% in this virtual South Africa in just a few years.

What this article offers is a mathematical model that satisfies donor demands to use the funds in a way that reduces the number of patients, and thus costs. Every individual would be expected to volunteer for a screening test at least once a year, and would agree to take medication every day for the rest of his life – not to take care of himself, but to contribute to the collective good by reducing the spread of the disease. Is this realistic? Data from the anthropological study[40] confirms that the discipline required of patients by public health policies runs up against the complexity of their lives.

39. R. M. Granich, C. F. Gilks, C. Dye, K. M. De Cock, B. G. Williams, "Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model", *The Lancet*, 373, 2009, pp. 48–57.

40. See in this work, Vanya Kovacic, *Social Navigation*.

What is most surprising about the "test and treat" proposal is the wide and rapid following it has attracted barely a year after its publication, despite the ethical dilemmas and considerable practical obstacles. What will happen to each patient's right to accept or refuse prevention? How can a proposal that at least doubles the number of people on ART become a reality within fragile public health systems where staff is in short supply, and the drugs have limited effectiveness and significant side effects? In reality, this proposal – more economic and political than medical – fits the situation that developed following the WTO Doha Agreement (2001) and the creation of the Global Fund (2002) perfectly. In those very specific circumstances, the States agreed to invest in treating patients despite the lack of prospects for eliminating the disease. Once that extraordinary and advantageous set of circumstances ceased to exist, talk of eradicating the disease started up again among HIV researchers and activists. What does it matter if there has been little progress in developing prevention tools, especially a vaccine; maintaining contact with donors means having to find a way to prevent them from losing impetus for economic reasons. Indeed, the slower growth of HIV funding is beginning to be felt. When asked about "test and treat," a high-level official[41] in Kenya's Ministry of Health confirmed his interest. In his view, it's simply a matter of financial resources. Ideally, This *Mwalimu*[42] supporter would prefer that his country provide the funding itself, because to him that seems the best guarantee of sustainable development. But in the absence of a national solution, he wants to see donors increase their funding sufficiently to cover treatment for everyone who is HIV positive. Yet Kenya is one of the countries where in previous years healthcare institutions weren't even able to put all of the international funding to good use. The interview with this high-level MoH official gave the impression – often experienced in other contexts – of an attitude that transnational funding of a public health initiative is equivalent to guaranteed income for administration officials. This feeling was to be confirmed by an interview with an officer from the National AIDS Control Council (NACC), then in full fundraising mode, and by the outside but involved view of an American Centers for Disease Control and Prevention (CDC) officer stationed in Kenya.

Testing an entire population every year and treating all positives with antiretrovirals – whether they need treatment or not – in order to stop transmission might be an appropriate approach in certain extraordinary situations. It is an experiment worth trying in high-prevalence areas where the epidemic cannot be controlled using other strategies and its impact is devastating. But as a list of the prerequisites (high prevalence, acceptability, and feasibility) makes clear, only rarely are all of these met. The Homa Bay region has twice the HIV prevalence of South Africa, the example for the "test and treat" model. Developing a similar strategy in this region would require mobilization and completely new forms of social organization; so little evidence of these is seen in MSF's day-to-day work that the goal of eradicating the epidemic in a few years seems highly unlikely. Given where HIV-fighting tools are today, reducing the disease's pressure on

41. The names of those interviewed will not be cited in this text. They were encouraged to be forthright in their comments on condition of anonymity.
42. A reference to Julius Nyerere, president of Tanzania from 1964 to 1985, nicknamed *Mwalimu* (the teacher), a fierce supporter of independent development policies vis-à-vis the former colonial powers.

society depends more on the ability of political and social actors to come up with entirely new forms of medical and social mobilization than on medical technology itself.

THE RETURN OF THE COMMUNITY HEALTH WORKER – FOOT SOLDIER AND SPECTRE OF PUBLIC HEALTH

The universal access to care and "test and treat" proposals agree on one point: that the resources needed to achieve the objective are to be found in community mobilization (a set of new behaviours by patients and those close to them who are not members of the medical or allied health professions). And so re-emerge the community health worker and community mobilization at the heart of the push for universal primary care in 2000 – a push that began at the 1978 Alma-Ata Conference. More than thirty years on, the supposed virtues of these community health workers are still at the heart of transnational public health discussions, as illustrated by an excerpt from an Institute for Development Studies[43] document: "Human resources are at the very heart of a health system. Health systems cannot function effectively without sufficient numbers of skilled, motivated and supported health workers; yet estimates suggest that there is a shortage of 4.2 million health workers worldwide. The shortage is most severe in sub-Saharan Africa. In countries where formal health workers are too few, Community Health Workers (CHWs), local level volunteers, have an important role to play in providing services to the poorest and most vulnerable communities. As CHWs are members of the communities where they work, they know and understand the health needs of those around them. Moreover, they can be trained and deployed quickly, and are unlikely to emigrate."

But meta-analyses of existing data – in particular data from randomized controlled trials, or RCTs – offer some nuance useful for understanding the impact to be expected from mobilizing the now re-named Lay Health Workers (LHWs). One of the largest literature reviews available[44] sums up the current state of knowledge: "Conclusions. The use of LHWs in health programmes shows promising benefits, compared to usual care, in promoting immunization and breastfeeding uptake; in reducing mortality and morbidity from common childhood illnesses; and in improving TB treatment outcomes. Little evidence is available regarding the effectiveness of substituting LHWs for health professionals or the effectiveness of alternative training strategies for LHWs." The current state of knowledge is itself a subject that warrants some clarification. Many studies focused on high-income environments; randomized trials on Lay Health Workers are poorly referenced in the scientific databases; not all of the studies in the literature review include a comparison between professionals and LHWs providing the same services; the studies comparing medical and allied health professionals to LHWs do not allow to draw a conclusion as to which category is better; the periods under review are too brief to give an idea of the effects of LHW activities beyond the short term; the differences in the amount of staff supervision between the studies and routine care needs to be accounted for in

43. Institute for Development Studies (IDS). "The UK Department for International Development (DFID) is the Institute's largest funder. IDS also receives funds from the European Union, various UN agencies, and a wide range of aid agencies, trusts and foundations". See http://www.eldis.org/download.cfm?downloadfile=5A2F2950-A58D-9352-CB5B5E0F1684A2D6&typename=dmFile&fieldname=filename.

44. S.A. Lewin, S.M. Babigumira, X. Bosch-Capblanch, G. Aja, B. van Wyk, C. Glenton, I. Scheel, M. Zwarenstein, K. Daniels, *Lay health workers in primary and community healthcare: A systematic review of trials. A policy brief prepared for the International Dialogue on Evidence-Informed Action to Achieve Health Goals in Developing Countries (IDEAHealth)*. [http://www.who.int/rpc/meetings/LHW_review.pdf].

order to assess the reproducibility of the effects noted; and overall, the available data do not distinguish well between failures due to poor implementation of the activities and those due to the chosen activities' lack of effectiveness.

In the case of Homa Bay, Kenya, several NGOs were given responsibility and funding by the government and international donor institutions to act at the community level. According to Kenya's strategic plan for HIV/AIDS, an estimated 60% of services at the local level must be provided by community service organisations (CSOs), members of the Kenya AIDS NGOs Consortium (KANCO). Created in 1990 by seven organizations, the consortium now has more than a thousand member organizations. Women Fighting AIDS in Kenya, or WOFAK, created in 1994, is one example of an organization working in a variety of areas: prevention and education for the most at-risk groups, advice for people with HIV, medical care, and advice on following the treatment. WOFAK runs ten centres, three of them in Nairobi, and estimates that it serves 6,000 women and 2,000 children. WOFAK representatives travel to sites and organize meetings with HIV-infected people in the villages. When questioned, heads of WOFAK in the Homa Bay district made no secret of the lack of resources and organization for doing their work. Thus, while organizations of this kind intend to act through people living with HIV or their close friends and family, the reality is that they do not have the material means to maintain a regular relationship with the people charged with conducting public health activities outside health centres and hospitals. What kept coming up, not just in the interview with WOFAK but also with representatives of other NGOs (the African Medical and Research Foundation, for example), was MSF's reluctance to pay for the contacts (transportation and food) between these organizations' representatives and those of the "communities" targeted by their action. In fact, in order to decentralize care from the district hospital to peripheral health centres, MSF was counting on the help of these very organizations who in turn asked MSF for help to be able to carry out their work.

The above give reason to doubt the results of a national and global strategy – universal access to treatment – that expects to achieve a highly ambitious goal using community mobilization as a cure-all to remedy the lack of appropriate technology and policies. That doubt is reinforced by the memory of similar situations with regard to health policy in general (e.g. the attempt to achieve universal access to primary healthcare), and to HIV in particular (early hopes of eradicating the spread of the epidemic through rapid, widespread adoption of new sexual behaviours).

SO WHAT DO WE DO NOW?

CAST ASIDE OUR ILLUSIONS AND KNOW OUR WEAKNESSES

There is nothing in MSF documentation or history to indicate that long-term public health responsibilities should be ruled out, *a priori*, because they are incompatible with the "MSF identity." We should, however, learn from past experience. The first lesson is that we should distance ourselves from fantasies such as universal access to treatment and "test and treat." Why talk about distance, and not about refusal? First, because these grand schemes for the future convey new health norms that legitimize resistance to unacceptable aspects of the present reality. These major transnational mobilization efforts deserve credit for putting issues, about which they were until only recently hopelessly apathetic, on the agenda of the world's most powerful. The new political dynamics offer us the option of joining a collective mobilization while maintaining a critical approach. But critical engagement is only advantageous if we can maintain real distance from the illusion at the core of the proposed policy. For example, believing it is possible to eradicate HIV with the tools now available implies that, while we might need to replace them, it is not essential. But in a context of chronically scarce public health resources, that which is needed but not essential quickly becomes superfluous. Thus, small advances as crucial as new diagnostic tests and drugs become less likely.

The second major lesson our experience should teach us has to do with our own limits. We do not have all the qualities required by certain aspects of health policy. In many African and Asian countries, in particular, pursuing "healthcare for all by the year 2000," or hoping to restore access to care after war, we have tried to improve the management of some public healthcare institutions by convincing the Ministries of Health to delegate to us the administration of some of them. To put it bluntly, while interventions of this type conducted from the early 1980s to the mid-1990s were educational, they were also resounding failures. Either the institutions were not at a stage where our objectives were realistic (free clinics following the Bamako Initiative, in an environment of structural adjustment), or MSF expertise and staff were a poor fit for their institution-building needs (the Expanded Programmes for Immunization). In addition to the unfavourable financial context of reduced public spending in the countries in question, we need to be clearheaded enough to see our own weaknesses: a private organization trying to consolidate public institutions, being foreign and the constant turnover in expatriate staff, many of whom didn't have the necessary qualifications for the task.

DESCRIBE AND UNDERSTAND WHAT IT IS WE'RE FIGHTING

First and foremost, the epidemic itself needs to be described at the level on which we intend to fight it – in this case, in the Homa Bay and Ndhiwa districts. The internal literature is full of provincial, national, and global information. We have relatively detailed information on the patient cohorts being treated. But one level is missing – the collective reality in which we practice. Here, this means the reality of the people in two rural districts in Kenya.

Medical teams should be paying attention to patients who are lost to follow-up – and more generally, to the people who aren't using medical services for which they are eligible. We should be adapting our services to the patients' culture and living conditions – not the reverse. Sociology and medical anthropology should be given greater autonomy in formulating the questions to be studied. While these questions are supplied exclusively by operations managers as terms of reference reflecting their own concerns and prejudices, social science studies are very likely to reinforce the opinions already widespread within the organisation, rather than shed new light on the problems encountered. Our current prevention and treatment methods are still very restrictive. To what extent, and in what proportions, can they be carried out? Only a combination of medical and sociological observation can answer this question.

INVENTORY AVAILABLE STRENGTHS AND KNOWLEDGE

The recent hire of a Kenyan manager in charge of partnerships with the other HIV actors in Homa Bay should enable us to get an overall view of the resources available in the two districts. Perhaps MSF should take the initiative by proposing a general meeting of everyone working on HIV in Homa Bay. In addition to the available resources, this would allow us to inventory the convergences and divergences between actors, and probably gain a better understanding of the patient associations' point of view.

In any case, once we have listed the resources and possible synergies, there will still be a large discrepancy between HIV prevalence and the means for combating it. MSF has the resources, particularly financial, which would allow us to recruit the personnel that are lacking. Similarly, we would be capable of covering the geographic area with community health workers deployed outside healthcare institutions. In the specific area of AIDS, past studies[45] have shown that such personnel can play an important role in patient follow-up. But the current literature on Lay Health Workers is quite clear about a potential systemic effect. There are no examples suggesting that the use of LHWs constitutes a decisive advantage in developing a sustainable healthcare system.

Fundamentally, doesn't an approach where tasks are allowed to slide down the chain of command (from specialist to generalist, from doctor to medical assistant or nurse, from

45. Jaffar S, Amuron B, Foster S, et al., "Rates of virological failure in patients treated in a home-based versus a facility-based HIV-care model in Jinja, southeast Uganda: a cluster-randomised equivalence trial", *Lancet* 2009 Dec. 19; 374(9707): 2080-9.

nurse to lay health worker) ultimately delegate much of the responsibility for treatment to the patient and the people around him (family, friends, patient associations)? In a number of countries – Burundi, for example – the large percentage of patients being treated in non-profit networks confirms this. The reasons for starting ART as early as possible are becoming clear. It's not only about the need for good individual care, but also the need to prevent an infected patient from transmitting the virus to too many other people. As a result, the number of individuals theoretically eligible for ART is growing, and is becoming increasingly difficult for the healthcare facilities to handle. More and more patients who are recruited or come in on their own will have an abnormal lab result, a detectable viral load, and no major clinical manifestations. Delegating a significant part of treatment responsibility to them, with support from the people around them, is probably the best compromise for ramping up the HIV response in places where the epidemic is most deadly, without excessive expansion of the public healthcare facilities to treat just one single disease.

The tools needed to implement this plan – even if only the antiretrovirals and lab tests – are not currently available. The need for a new fixed-dose antiretroviral combination – at a price where over ten million treatments a year worldwide would be feasible – is becoming clearer every day. It will have to be more robust against resistance, tolerant of irregular dosing, relatively insensitive to weight variations, and have less severe side effects. The number of lab tests that can be done rapidly in resource-poor settings is growing quickly. The HIV antibody test and CD4 count are already available in this form, and the viral load soon will be. Imagine patients going to a walk-in counter near their home or work to be screened, starting treatment based on lab criteria before their immune systems are too damaged, being monitored for treatment efficacy using simplified lab tests (rapid CD4 count and viral load) and, if there are no major abnormalities, getting their ART prescriptions renewed without seeing a doctor or nurse. The only piece missing from this primarily laboratory-based system for monitoring HIV-infected people before they show clinical signs of the disease is a lab test able to tell whether the patient is following the treatment. This is one specification that could be included when developing a new fixed-dose combination to take over from the current first-line treatment. Wouldn't it be possible for the new FDC to include a marker that would indicate, via a simple lab test, good treatment compliance? But laboratory tools will only be useful if they are in line with, as much as possible, patients' wishes. No matter how sophisticated the available tools, care-provider teams and patients will have to decide together on a treatment protocol. A change in the first-line treatment – which will be unavoidable due to treatment failures and side effects – offers an opportunity to examine what patients, and the clinicians who follow them, want from the new treatment.

Testing new approaches requires an appropriate working environment, which a partnership with KEMRI[46] – the national medical research institute – could provide. The

46. "The Kenya Medical Research Institute (KEMRI) is a state corporation established through the Science and Technology (Amendment) Act of 1979, as the national body responsible for carrying out health research in Kenya."

fact that KEMRI and MSF are both founding members of the Drugs for Neglected Diseases initiative bolsters the idea of a partnership with enough autonomy to develop alternative approaches outside, or on the fringes of, the public system's treatment protocols. The hope is that, having been studied by the national medical research institute, these alternatives can some day be adopted by MoH healthcare centres.

Obtaining better tools (drugs and lab tests) is part of the transnational dimension of the fight against HIV. The specific needs of medical research for patients treated in resource-poor settings, the ins and outs of medical product marketing, and public health financing remain central issues. Ten years ago, thanks to the legitimacy it gained with its early treatment successes in places where they had been thought impossible, MSF helped advance these issues. It enabled the Association to state the problem it was facing in simple terms: "Our patients aren't dying due to the virulence of infectious agents, but because of the unjustifiably high prices of the drugs that could save them." It's easy to understand the power of this public statement, and its devastating effect on the positions of the interest groups involved – for example, the Big Pharma and the donor states. The contemporary equivalent of this powerful lever would be a demonstration that the epidemic can be controlled at the local level. Then, drawing on this new expertise, MSF would again be justified in demanding publicly the resources needed to control HIV in the places where it is taking the greatest toll.

APPENDICES
Appendix 1

HOMA BAY PROJECT TIMELINE

1996

MSF responds to clashes between two clans in North West Migori with mobile clinic for a few months.

MSF upgrades Got Kojowi Health Centre as a referral centre for a Home Based Care Programme in Nyarongi Division to address the HIV/AIDS situation.

Introduction of HIV testing.

1997

The Home Based Care project is discontinued due to increased activities at Homa Bay District Hospital and poor uptake of services.

Activities focused around TB care are rolled out.

1998

A blood safety programme begins at Homa Bay District Hospital and is continued until 2004 when the Kisumu Regional Blood Bank becomes operational.

1999

An outpatient HIV clinic opens in 3 rooms of the hospital to treat sexually-transmitted infections and provide prophylaxis.

The Inpatient Pharmacy Programme (IPP), a revolving fund pharmacy, begins in 1999 to address the shortage of drugs in the medical wards. It is subsidized by MSF until 2004 and then fully handed over to the Hospital Administration in December 2008.

2000

Water and Sanitation works: waste zone, grey water drainage system and connections between the water system and borehole are carried out; hygiene products are supplied to the whole hospital until 2004.

2001

The first HIV positive patient is started on ART on November 15, 2001 – the first in a public facility in Kenya and completely free of charge.

2002

Peripheral TB activities in 27 sites together with the Homa Bay District.

2003

HIV mobile clinic activities start at Ndhiwa Health Centre – stable patients from Homa Bay District Hospital are decentralized to Ndhiwa.

MSF and the Ministry of Health organize a national symposium on access to ARVs to convince other partners to engage in HIV treatment.

2004

HIV mobile clinic activities start at Rangwe Health Centre and Magina Health Centre.

Construction of outpatient clinic for HIV services – the MSF HIV clinic moves from 3 rooms to an entirely new facility located on the hospital grounds.

The Ministry of Health starts an anti-retroviral programme in the former clinic area used by MSF.

2005

MSF introduces Ready to Use Therapeutic Foods (RUTFs) in its HIV programme for nutritional support.

Ward 7 – the TB Ward – is renovated by MSF to improve separation of patients and an isolation cubicle is created.

2006

MSF starts the first patient on treatment for multidrug-resistant TB.

MSF introduces the 6-month regimen for TB and provides all the TB drugs for Homa Bay District.

ARVs become free in the public sector programme and integration of the MoH and MSF HIV Clinics begins with creation of Clinic "A" for stable patients and Clinic "B" for initiation and more complicated cases.

Isolation cubicles in both adult medical wards are rehabilitated by MSF.

2007

PMTCT becomes an important focus for the project and a partnership is developed with the MoH Maternal and Child Health department and NARESA (Kenyan NGO) to create a "One-Stop" service for HIV-positive pregnant women.

A counselling room is constructed in front of the Chest Clinic to increase and improve testing and counselling of TB patients.

"One-Stop" service for TB-HIV co-infected patients begins in the HBDH Chest Clinic.

March 2007 – MSF opens the TB culture lab in the newly constructed extension of the laboratory.

MSF and Homa Bay District Hospital sponsor a direct line to the water system ("bypass") to improve the volume of water.

2008

Ambulatory drug-resistant TB programme is started for non-infectious patients during the intensive phase with the creation of a patient hostel in town (Kabissa House).

During the period of post-election violence, an MSF mobile team provided support to the ART satellite sites of Homa Bay District Hospital to ensure adequate supplies throughout the district.

2009

Jan 2009, the supply of adult TB drugs for 6-month regimen is successfully handed back to the National Tuberculosis Leprosy Programme. MSF continues to provide the paediatric packs.

Start of decentralisation of treatment for drug-resistant TB for non-infectious patients in the continuation phase of the treatment.

In Homa Bay District Hospital, Ward 6 is renovated into Side A for Paediatrics and Side B for drug-Resistant TB patients.

Sep 2009 - Extension to Clinic "B" completed - physical merger of the two HIV clinics in October and enhanced counselling activities in Clinic "A" in progress.

Sep 2009 - 5 additional health centres providing anti-retroviral drugs for HIV are included in HIV decentralization programme for technical support in coming months.

Full harmonization of MSF and MoH cohort is achieved in October when all ART-related laboratory baseline tests are provided free of charge to HIV-positive clients in Homa Bay.

2010

Ambulatory drug-resistant tuberculosis care and treatment programme (intensive and continuation phases).

Full integration of Preventing Mother To Child Transmission services into ante and post-natal care at Homa Bay District Hospital.

Improved quality of care in antiretroviral therapy satellite sites through provision of technical support to government sites.

Appendix II

HOMA BAY PROJECT

Event/reason for intervention: Victims of HIV/AIDS epidemic and Drug Resistant Tuberculosis

Type of population: General population of Homa Bay District.

Duration of the project: Home based care started in 96/97, TB care in 97, blood safety in 98 and HIV prevention services and STI management started in 1999 in HBDH, since 2001 MSF is providing ARVs

International staff: 5   **National staff:** 98 project staff

Budget: 1,968 KEuro

Context

Homa Bay district (including Ndihwa district) has a population of around 350,000. A conservative estimate of HIV prevalence is about 16% among people aged 15 to 49. Other estimates of prevalence reach 30%. MSFF started HIV/Aids activities in 2000 and introduced free ARVs in the Homa Bay District Hospital in 2001. In 2004, the Ministry of Health (MoH) started its own HIV/Aids activities in the hospital. Integration of the two programmes started in 2006 and was completed in October 2009. Activities concentrate on outpatient care with only very limited involvement in the hospital wards. Decentralisation activities until last year were focused on three clinics on a relatively small scale. Though it started HIV/Aids care in the district, MSFF is now surrounded by different actors badly coordinated by the MoH with Pepfar (The U.S. President's Emergency Plan for AIDS Relief) sponsored Aphia II (AIDS, Population and Health Integrated Assistance) being the actor with major influence in the district, despite being barely active in the district hospital. MSF also provides TB and Multidrug-Resistant (MDR) TB care in cooperation with the national programme and runs a culture laboratory in Homa Bay district hospital.

Review of 2009

MSF continued its work in the Homa Bay District Hospital (HBDH) HIV clinic, the 2 hospital medical wards, the tuberculosis ward, the chest clinic, and 3 peripheral health centres (Ndihwa, Rangwe and Magina). Additionally, another 5 MoH health centres in the district were approached and assessed to start decentralisation activities towards the end of the year. The decentralisation strategy was re-modelled from a substitution to a

consulting/technical support approach. Two of the former three health centres are now running independent activities with very limited involvement from the MSF team. Major obstacles to a more swift extension of activities were Aphia II's reservations and the MoH's lack of coordination in the district. As of January 2009, the MoH (Pepfar) mainly supplied ARVs, with several stock outs due to a lack of clear cohort data, order discipline and stock management by the MoH and KEMSA (Kenya Medical Supplies Agency).

The two cohorts were finally fully merged in the extended Clinic B facility, which was completed in 2009. The MDR "Ward 6" was completed and officially inaugurated in August.

Efforts were made to improve defaulter tracing, with MSF leading the set-up of a coordinated tracing through CBOs (Community Based Organisations) and NGOs in the district. The recruitment of a department supervisor and the involvement of an outside counselling advisor were intended to improve the counselling department's performance.

Medical Activity Summary

HIV cohort			
Total Patients	9,400 Under Followup (Nov 2009)	6,762 on ARVs (Nov 09)	Dec 2009
New inclusions	213 under followup	121 on ARVs	Avg/month 2009
Stage 1 or 2 %	45.8%		Average 2009
PMTCT inclusions	545		Total 2009

TB	MDR	PDR	Non-resistant TB	
Patients under care	13	3	212	Dec 2009
Patients inclusions	14	1	460	In 2009

Objectives 2010

1. Continue provision of access to HIV/TB care for the population of Homa Bay district in close collaboration with the MoH and intensified efforts to share management components to the MoH staff

2. Enforce HIV/Aids decentralisation activities in the 5 new health centres avoiding substitution and concentrate on supportive activities and consultancy leading to harmonization of the HIV program across all 8 satellite sites.

3. Further decentralize MDR treatment towards a community based approach.

4. Facilitate improved MDR detection through quality laboratory analysis.

5. Translate the so-called 'access for more' strategy into activities on the ground and define a research-result based approach towards the goal of accessing more patients at an earlier state of infection

6. Improve access for all mothers to testing and PMTCT (Preventing Mother-To-Child Transmission) programmes in the GoK dispensaries and fully integrate the HBDH PMTCT programme into antenatal and postnatal care centres.

7. Aphia II Nyanza financing will end towards the end of 2010. A timely involvement in the expected set-up of Aphia III should be considered in order to improve collaboration between all partners in the district.

8. Set up a definitive, solid and appropriate sustainable power solution for the hospital lab.

9. In close collaboration with Epicentre, look into innovative medical research subjects such as viral load study, point of care CD4 validation, Kaposi Sarcoma treatment, first-line failure, etc.

10. Launch of the Valid® study on nutrition for HIV/Aids patients.

MAP Feedback Kenya
June 2010

Operational Philosophy
Medical needs (Mortality /Morbidity)
Plus at least one of the following:
Causality
Conflict, epidemic, natural disaster
Value added MSF
Institutional interest (developing trauma surgery, missionary hospital, advancing HIV treatment)

Evolution of HIV in MSFF France
Late 90's – No and nothing to offer
Early 2000 – Yes and good early success (treatment and advocacy)
Mid 2000 – dissatisfaction on multiple levels
    Field – questioning the pertinence of operations
    Paris – questioning pertinence, money and the role of MSF
2007-8 – Concentrate on sickest patients – pull back from large cohorts
2009 – Recommitment of MSF role in HIV care
    1 – Still an emergency
    2 – Big gaps in understanding treatment capacity still exist and new diagnostic tools may facilitate operational changes
March 2010 – Intersection HIV meeting: very few new ideas came out of the discussion. The suggestions on innovation amount to applying things that we know how to do.

The future…
While respecting the work that has been done in the projects and the fact that now we treat many patients, all levels (desk, coordo, field) recognize the stagnation of the HIV programmes and share the common goal of accelerating the advance of HIV operations. We have a choice to make – do we continue to improve the projects incrementally or set a long- term objective for treatment? The desk believes that we have to set a long-term goal for each project that will drive us towards something more than incremental achievement in order to break from the cycle of dissatisfaction with the current programmes.

Mathare

…

Homa Bay

Strategy – Access for More. The target for the programme is coverage. For the next MAP, the team is expected to provide:

Estimates of current coverage (either from a study or compilation of existing data) (July)

Re-write the future orientation of the programme slide 35 based on the Access objective (August).

A coverage goal – specific percentage/patient numbers (Sept).

Plan for re-orientation of activities to meet coverage objective in the coming 24 months.

Defend strategy for access versus incidence reduction. Why not go further and try to reduce transmission via access and treatment?

Protocol: Goal is to begin shift of patients to 350 and Tenofovir immediately. Team needs to reflect and devise proposal for transitioning patients to ensure that, by the end of the year, 350 is the threshold in all the programmes that MSF supports and all new patients are put on AZT or TdF. An initial discussion must take place very quickly to figure out the short-term budget impact as we assume that MSF will need to pay for the bulk of these new treatment costs.

Dispensaries: MSF will handle drug delivery at the dispensary level (23 dispensaries). The goal is to ensure that diagnosis, counselling, and treatment for HIV/TB is available. Given the current period of transition between Aphia 2 and Aphia +, we feel that it is important to get an agreement with the MOH for this activity and then communicate broadly to Aphia and USAID that MSF is moving into this space. Timing – the goal is an agreement with the MOH by August 15th and implementation in at least 10 health centres by the next MAP. The approach to this can be sensitive to the relationships and partners in the area as long as it meets the time objectives.

Laboratory: We continue to debate MSF's role in adding resources to the HIV side of the lab. We need a definite plan to have adequate access to CD4 services for HB (including dispensary scale-up and 350 threshold) plus all necessary tests to support TdF protocol. Note that the CD4 plan should consider the use of point of care in the future. Electricity must be solved; if it is not solved by the next MAP, Fred is buying us all dinner!

DR TB: Ok to support acceleration of DR TB care in surrounding health districts with technical support (should we try to negotiate MSF protocol in exchange?)

Training: Agree that training is an essential element in quality as well as staff motivation.

Ok to invest in training resources but not clear that a 'training centre' is the right approach to start off with. First need to define a post for training advisor (expat or national) who will help develop curriculum, organize training, but not necessarily lead training.

Education-Communication: Agree that more public messaging on HIV is necessary. Agree to pursue suggestion to communicate via the local Luo radio station. An HIV education/prevention message needs to be developed and tested in the community before any radio campaign; could be a good place to link up with other organizations.

Anthropologist: Very interested in the concepts arising from the interviews of patients coming in late.
Need to finalize orientation of remaining time in the programme. I propose understanding why patients come in early (essentially the same research on health seeking behaviour for patients who come in when they are healthy). Although potentially fraught with problems, it would be interesting to actually interview health workers on their barriers to providing treatment (health providing behaviours?).

Coordination
Expat duration: 9 months with case-by-case evaluation of extensions; they will not be categorically refused but the desk remains committed to supporting the rotation of expats.
HQ agreement: need to closely monitor implementation.
CQ: OCBA is sending a security advisor; team will review recommendations and make proposition if changes are necessary.
Night driver: would like plan for hiring a night driver and elimination of expat driving. This will also help with the transit problem where you could give the per diem and security rules to the driver who goes to the airport.
Academic MedCo: not approved based on the priority to establish the strategic direction of the programmes and the fact that the current Asst MedCo is apparently not ready to assume these responsibilities. Coordo can assess needs for a Deputy MedCo.

PART 3
Cultural stereotypes and the health seeking behaviour of HIV/AIDS patients in Homa Bay, Kenya

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I. INTRODUCTION

1.1. "AFRICAN SEXUALITY" AND THE SPREAD OF HIV

Homa Bay is located in the western part of Kenya, one of the areas in the country most severely affected by HIV. The estimated prevalence is 14% higher than the national prevalence (Chiao et al., 2009; MSF France, 2009; National AIDS Control Council, Kenya, 2005), which inevitably leads us to the question: Why this is is this the case in Homa Bay and not in other parts of Kenya?

The reasons for this disproportionate distribution of HIV are frequently attributed to the cultural practices and traditions of the Luos, an ethnic group predominant in western Kenya. Luo culture, with polygamy, sexual cleansing rituals, and wife inheritance,[47] has created a fertile ground for culturalistic[48] discourses on the spread of HIV in Kenya among scientists, medical specialists and the Luos themselves.

Dating back to colonial times, these are certainly not new. Literature from the period abounds with explanations on the spread of specific diseases, particularly sexually-transmitted ones, and how this relates to the culture and behaviours of local African peoples. In the 19th century, for instance, there was a simultaneous outbreak in Uganda of non-sexually transmitted treponema pallidum pertenue (yaws) and sexually transmitted treponema pallidum (syphilis). Both infections were attributed in the medical texts to the "immoral behaviour" of Africans (Vaughan, 1991). Africans were not only seen as looking different and being susceptible to disease, but also as having different sexual inclinations and behaviours, which went on to become defined as "African sexuality" (Caldwell et al., 1989).

47. Sexual cleansing rituals, regulated by strict rules, are still practiced particularly in rural areas of Nyanza province to celebrate planting and harvesting, childbirth, etc. Widows are expected to undergo such rituals after a period of mourning to honour the memory of a dead husband and free themselves to re-marry. Widow inheritance is often related to both rituals that last only a couple of days, to remarriage, which is a longer commitment to the new husband who, according to tradition, should belong to the family of the deceased.
48. We use the term "*culturalistic*" to refer to the broad definition of "culture" as a set of shared attitudes, goals, beliefs, behaviours, practices, etc.

"African sexuality" was divided into two categories: male and female sexuality, and female sexuality, with the latter becoming the focus of some considerable colonial attention. The black African woman was described as degenerate, primitive, and passionate and was used as a synonym for the prostitute and the female animal. She was described as "doubly dangerous, being both African and wild, and female and wild", (139:1999). She was an icon of sexually- transmitted disease, in contrast with the women of 19th century Britain who were seen as "reproducers of race" and whose female sexuality was "successfully tamed" (Vaughan, 1991).

During the initial stages of the HIV epidemic, such racial stereotypes were used to determine attitudes towards the spread of the disease. But as "race" went on to become a more sensitive issue in the scientific arena, arguments on specific cultural traits fuelling epidemics became a convenient substitute.

1.2. LUO CULTURE AND THE SPREAD OF HIV

In the case of the Luo ethnic group, the notion of a culturally-driven spread of HIV is deeply rooted and, surprisingly, even now has not moved on from the colonial perception. *Culturalistic* approaches appear not only in peer reviewed scientific papers (see for example Ayikukwei et al., 2008; Ogoye-Ndegwa, 2005), but they are also common among healthcare providers, including MSF (see End of Mission, Kenya (2003-2007) internal report).

There is doubtless an intuitive reasoning behind *culturalistic* arguments. Sexual cleansing rituals, wife inheritance, and polygamy are slowly dying out, but they still play an important role in everyday life in the rural areas of Luoland. However, who is best placed to talk about their culture? Here is what the Luo elders have to say about the spread of HIV:

"In the old days, younger people respected older people, but not anymore. And people never used to die like they die today. Men in the old days, they were between 23 and 25 (years old when they got married), but now even 15-year olds get married. Women used to get married at the age of 19 or 20. In the old days, younger women respected their parents, they waited (sexual activity) until the right time! They waited until they got married. And parents needed to approve the marriage. In fact, in the old days, girls got married as virgins, but not anymore. The girls, once they got married, they would stay there (at home), even if they were young. People would not go anywhere else (to have extramarital affairs), it was not the custom at all! But now it doesn't happen that way. Right now, girls go out to look for money from the men. They engage in sex for the sake of money, to help their parents. And in the old days there was no disease (AIDS). But there is a disease now and it is killing people, so people depend on other people to look after them... So people engage in sex for the sake of money. There are a lot of

nightclubs, discos. And there are young men and they marry young girls without their parents' consent. These younger men work as casual labourers. So they keep the money and at night they go to discos and they get diseases there. And again, when they go home it is the responsibility of the older people to look after them when they fall ill. So it is a problem...

Wife inheritance in the old days, it was done for the sake of the children. Then women could not look after their children alone. Food, clothing, basically the man took care of them. But nowadays, even older women remarry younger men, which is disrespectful. In the old days, there was wife inheritance but (it was regulated), it had to be a brother-in-law, whose background was known about by the lady (widow). And the older people needed to sit down to discuss and they had to approve, before the inheritance took place. But nowadays, in modern times, it is not like this anymore... People go and marry just anyone. And it is even worse, because of this disease, this deadly disease (AIDS). Now people just marry at random" (Elder, Homa Bay, 19/4/2010).

The elders, who have witnessed their community struggle with HIV for decades, are stating very clearly that it is not ancient Luo culture, but a change in this culture - a shift in the way it is practiced or the practice of this culture with very different rationales - that is the reason for disease, death and an aggravation of health and social issues. An important point they make is that the culture, wife inheritance, for example, was regulated and governed by certain rules and that the elders were responsible for ensuring that the codes of conduct were heeded in accordance with the rationales on which they were based. The advent of a more western lifestyle with its discos and so on, a loss of respect for erstwhile social rules regarding marriage, the access to cash-paid labour and the HIV epidemic itself, exerted new existential pressures on the community and contributed to the spread of disease far more than the "old" Luo culture. According to the elders, had this "old" Luo culture remained untouched, it would have, on the contrary, fought to prevent HIV infection. Furthermore, so far, no sound epidemiological evidence has been offered to support the *culturalistic* approach on the spread of HIV or weigh it against other debates centred on economics or physiology.

1.3. WHO IS GUILTY AND WHO IS RESPONSIBLE?

It does not matter which – racial stereotypes, such as "African sexuality" or the cultural uniqueness of the Luos – both have been successfully used from the outset of HIV control in simplifying discourses on the spread of HIV until now. While it is taken for granted that polygamy and prostitution are responsible for the spread of HIV in Africa, nothing much is said about HIV infection caused by medical intervention. However, when Gisselquist et al. (2003) examined crude risk measures for HIV infection in Africa through to 1988, they provided evidence that exposure to healthcare caused more HIV than sexual transmission, promoted as the main means of transmitting the disease. Furthermore, the authors argue that this evidence was deliberately ignored in order to maintain public confidence in the

healthcare sector. Thus, as often happens, *culturalistic* approaches are automatically defined to represent the culture of patients or communities but ignore the powerful, possibly even more dominant culture perpetuated by healthcare systems and their medical interventions. In fact, the latter are rarely called into question.

Thus, the will to maintain public confidence in healthcare often results in biased views. The example of health seeking behaviour we present in this paper discloses details of one such bias and further suggests that blaming the patient is commonly used to divert responsibility from healthcare providers who contribute substantially to the problem. It is important to keep this in mind, since attitudes to HIV epidemics have always been inseparable from individual, cultural, national, and international blame. Much caution is necessary because a *culturalistic* approach may be used not only to over-simplify the complexity of an issue, but also as a reason to justify inequitable distribution of healthcare in the future. Unfortunately, in times when sustainable ART funding is uncertain, this is not mere conjecture.

II. WHY DO PATIENTS DELAY IN ATTENDING FORMAL HEALTHCARE FACILITIES?

One issue stemming from the *culturalistic* approach became apparent to us during our research on health seeking behaviour[49] among Luo patients. The question was: why do some patients take so long to access HIV-related treatment? The question originated from the observation of numerous patients in Homa Bay hospital wards who are bedridden and suffering from severe forms of opportunistic infections. During discussions with health workers we realized that the common assumption is that these patients prefer traditional treatment to formal western treatment since it is an intrinsic part of their culture. The other assumption was that they wait to be very ill before going to a formal medical institution. Hence, these common assumptions are based on the patients' culturalistic beliefs and clearly imply that the solution lies in exploring and changing their attitude.

As will become apparent, the results of this research showed that culture did not play a major role in keeping patients away from medical facilities, or at least not the culture practised by the communities in question. But, the medical institutions and the culture they perpetuated did contribute to creating barriers to early treatment. This of course opens a fraction of the blame mentioned above and provides the opportunity to initiate a discussion on the sharing of responsibility between patient and healthcare provider.

49. Health seeking behaviour refers to different treatment options used by patients, with the focus on the reasons for their choice and the factors that contribute to associated decisions.

Health seeking behaviour is often examined, as was our research, to steer patient behaviours towards institutionally desired actions. Healthcare providers promote HIV testing and early treatment of HIV-positive individuals because these have many advantages: easier administration of treatment, less side effects, and better prospects of recovery before the onset of medically-challenging opportunistic infections such as TB, meningitis, Kaposi's sarcoma, etc. (Harries et al., 2004). In addition to the physical benefits, patients also profit from early treatment in social terms since the symptoms of the initial stages of the disease, such as skin disease and severe weight loss, show little or not at all which prevents them from being stigmatised. Moreover, they remain fit and are able to work and support their families. So, the benefits of early treatment are not under debate here, but rather the means to achieve them.

It is manifest from the medical records that a high proportion of patients are extremely slow in going to MSF France-run Clinic B. The interviewed patients, for instance, received HIV-related treatment a year and a half later on average, when there was already a strong suspicion of HIV. This suspicion stemmed either from their partner's disclosure of their HIV-positive status or from their own persistent symptoms of opportunistic infections. Here is a review of what happens during the lengthy period before patients take up the treatment programme.

2.1. WHERE DO PATIENTS GO FOR HELP?

The diagram below is based on the analysis of interviews with 50 patients (25 male and 25 female); for more details on methodology, refer to Kovacic V. (2010), Operational Report I. Each patient's account was plotted as a set of pathways, joined in Diagram 1.
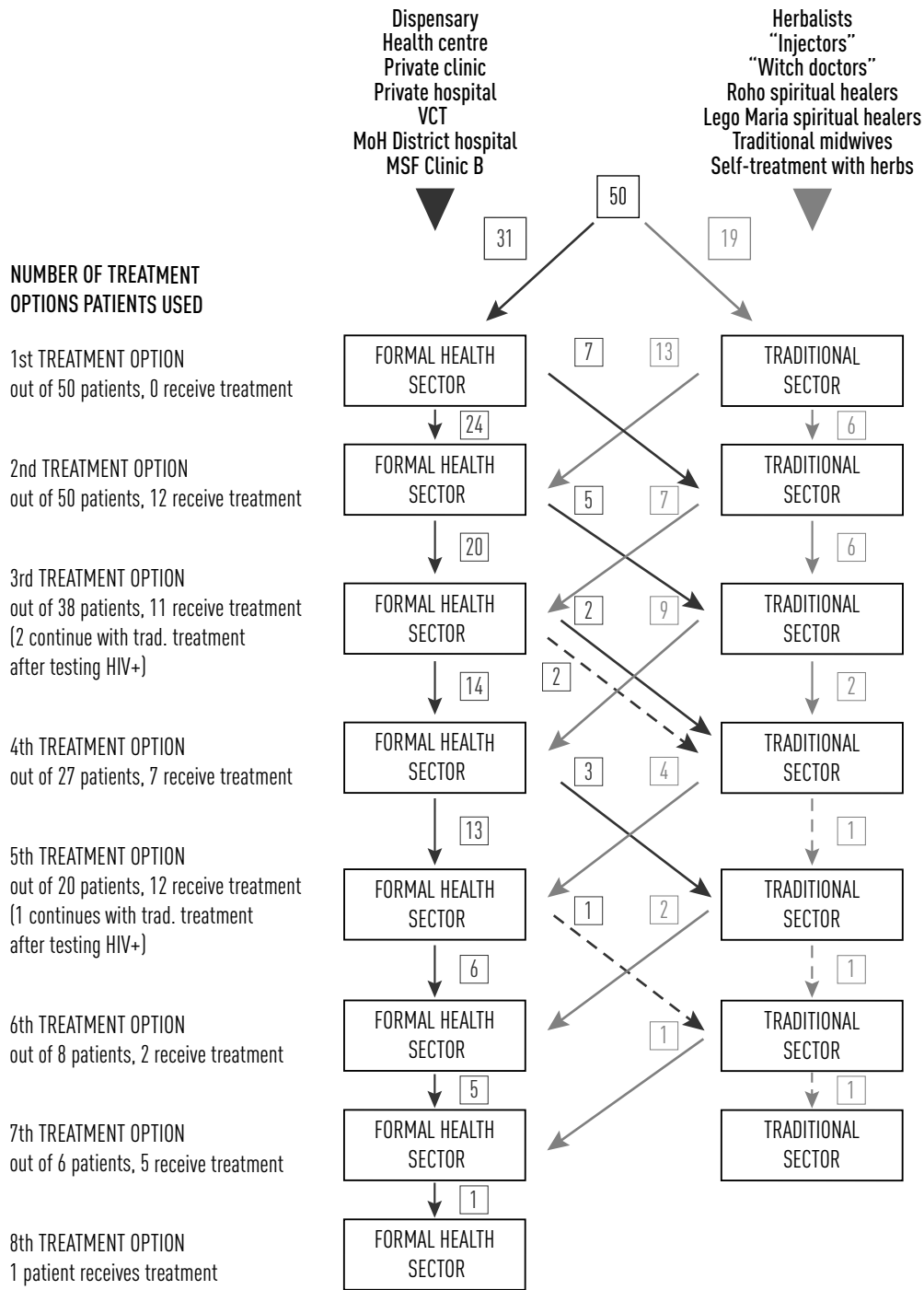
Analysis of the health seeking pathways (the steps that patients took and the treatment options they used prior to receiving HIV/AIDS treatment) gives cause for alarm. More than half of the patients (62%) began in the formal healthcare sector such as dispensaries, private clinics, district hospitals, etc. where they could be tested for HIV. Failure to diagnose patients with HIV during the first four visits to a healthcare facility was on average 74% (1st visit: 100%, 2nd visit: 68%, 3rd visit: 59%, 4th visit: 74%, 5th visit: 40%, 6th visit: 75%, 7th visit: 17%, 8th visit: 0%). Furthermore, over half (57%) of the patients had to take at least 4 different steps before receiving satisfactory treatment. The maximum number of steps reported before receiving appropriate treatment was no less than eight.

This leads us to conclude that, despite HIV/AIDS being a major public health issue in the area and that patients regularly access formal healthcare facilities, the ability to diagnose an individual with HIV in these facilities is extremely poor. Hence, the poor rate of suspicion (a clinician's ability to suspect HIV infection) and diagnosis (lack of technical capacity) were major reasons for delays in treatment.

In spite of this, in comparison to traditional treatment, the formal healthcare sector leads the way in the health seeking process; patients' flow is considerably higher (on average 19 patients per step) compared to the traditional sector (on average 7 patients per step). More than one third of patients (34%) turned to traditional health systems as a second option after becoming disillusioned with the ineffective treatment provided at formal healthcare facilities. But, out of the 19 patients who began with the traditional healthcare sector, 68% turned to the formal healthcare sector as their next treatment option.

In short, the formal healthcare sector is the leading treatment option chosen by patients when confronted with HIV-related symptoms. Poor diagnosis results in treatment that does not relieve symptoms. This leads to substantial intervals before the next visit to a formal healthcare facility and impacts on opting for traditional treatment as an alternative.

Diagram 1: Patients' pathways (based on 50 patient accounts)

Dispensary
Health centre
Private clinic
Private hospital
VCT
MoH District hospital
MSF Clinic B

Herbalists
"Injectors"
"Witch doctors"
Roho spiritual healers
Lego Maria spiritual healers
Traditional midwives
Self-treatment with herbs

50

31   19

NUMBER OF TREATMENT
OPTIONS PATIENTS USED

1st TREATMENT OPTION
out of 50 patients, 0 receive treatment

FORMAL HEALTH SECTOR   7   13   TRADITIONAL SECTOR

24   6

2nd TREATMENT OPTION
out of 50 patients, 12 receive treatment

FORMAL HEALTH SECTOR   5   7   TRADITIONAL SECTOR

20   6

3rd TREATMENT OPTION
out of 38 patients, 11 receive treatment
(2 continue with trad. treatment
after testing HIV+)

FORMAL HEALTH SECTOR   2   9   TRADITIONAL SECTOR

14   2   2

4th TREATMENT OPTION
out of 27 patients, 7 receive treatment

FORMAL HEALTH SECTOR   3   4   TRADITIONAL SECTOR

13   1

5th TREATMENT OPTION
out of 20 patients, 12 receive treatment
(1 continues with trad. treatment
after testing HIV+)

FORMAL HEALTH SECTOR   1   2   TRADITIONAL SECTOR

6   1

6th TREATMENT OPTION
out of 8 patients, 2 receive treatment

FORMAL HEALTH SECTOR   1   TRADITIONAL SECTOR

5   1

7th TREATMENT OPTION
out of 6 patients, 5 receive treatment

FORMAL HEALTH SECTOR   TRADITIONAL SECTOR

1

8th TREATMENT OPTION
1 patient receives treatment

FORMAL HEALTH SECTOR

N°   Number of patients who have chosen this treatment option
⟶   Path away from formal healthcare sector
⟶   Path away from traditional healthcare sector
-- ➤   Move to traditional treatment, regardless of HIV test/treatment

2.2. INSTITUTIONAL DENIAL

When the patients who used formal health facilities as the first option were successfully diagnosed, this was the end of their long health seeking behaviour. In relation to this, we use the term "institutional denial" to refer to institutional neglect and resistance (whatever the reason) to diagnose patients with HIV, even when the symptoms clearly indicate the likelihood of HIV infection.

Let's look at the example of the patient who went to Ndhiwa district hospital[50] with persistent diarrhoea. Despite being an obvious symptom of HIV infection, she was treated for typhoid for two years and was never offered an HIV test during her visits to the formal healthcare facility. Another example is a patient who, during a couple of repeat visits to the MoH division of Homa Bay district hospital (an extension of the MSF HIV/AIDS care unit) was treated for "serious malaria". After a lengthy and frustrating period with no improvement in his symptoms, he was at last offered an HIV test.

The conditions most commonly treated early on in health seeking behaviour were malaria and typhoid. Not surprisingly, patients who were disillusioned with ineffective treatment turned to traditional methods as an alternative and it took them a long time to decide to return to the formal facility. This decision was also fuelled by a traditional explanation of diseases in the event of diagnostic failure in healthcare facilities: "*If someone suffers from Luo diseases, tests in the hospital do not show anything in the blood*".

Hence, in contrast with reasoning delays in treatment with patients' lack of urgency (ability to seek healthcare), improved HIV-infection testing capacity, insufficient in the formal healthcare facilities, is required in order to detect more HIV infections in the early stages of the disease.

2.3. TRADITIONAL TREATMENT

Despite the predominance of the formal healthcare sector, traditional treatment was frequently used by the interviewed patients (a total of 72%), and remains an important treatment option in health seeking behaviour. The following description provides some insight into the practices used and evaluates the conceptual interaction between traditional healers and the formal healthcare sector.

Traditional treatment is provided by traditional healers ("witch doctors", herbalists, traditional midwives[51]) and religious healers, mostly from independent churches Roho and Legio Maria. Traditional treatment involves drinking herbal infusions, licking dried herbs, using herbs for bathing, and superficial cutting of the skin and application of herbs. Spiritual healing includes praying, sprinkling blessed water over the patient, and drinking blessed water.

50. District hospitals are at the top of the organizational structure of the local healthcare system. This implies they have far greater resources, medical staff and equipment compared to lesser health units. In theory, they are equipped to carry out HIV diagnosis and follow-up.

51. While "witch doctors" and religious healers profess spiritual powers, traditional midwives and herbalists claim to have technical skills only, knowledge of herbs and abnormal physical ailments, for example

This type of treatment is associated with the diagnosis of two different traditional diseases, *chira* and *witchcraft*[52] (more details on traditional treatment in Operational Report I).

In support of the criticism of the *culturalistic* approach, none of the interviewed healers claimed to be able to treat or cure HIV/AIDS. On the contrary, they were very clear that this is the domain of the formal healthcare sector ("*hospital disease*", as they call it). Some of them, when they saw their clients' symptoms, even said they suggested to them the possibility of HIV and referred them to the nearest healthcare facility. Therefore, in some circumstances, the local culture works in collaboration with, rather than against, the formal medical institutions.

III. CONCLUSIONS

Racial and cultural stereotypes have been used from the early stages of HIV/AIDS control to explain the specifics of HIV distribution in Africa. Unfortunately, the same principles are applied when healthcare providers struggle to explain poor access to medical facilities providing HIV-related care. Through the example of the health seeking behaviour of HIV patients who delay accessing HIV-related care, we see that culture, namely the traditional interpretation of symptoms and traditional treatment, is only a very small part of the problem in Homa Bay. In contradiction with common assumptions regarding patient and community culture determining care-seeking and delayed treatment, long delays in accessing treatment were mostly due to the failure of the formal healthcare sector to diagnose these patients with HIV when they accessed health facilities earlier in health seeking behaviour. This example demonstrates the need to conduct a critical evaluation of the provision of quality care in MSF's operational area. It also opens up debates on the pertinence of our perceptions of programme beneficiaries and our assumptions regarding the cultural determinants of health seeking behaviours. A critical approach, based on evidence from the communities/beneficiaries but examined and analysed impartially without cultural stereotyping, would enable the development of effective HIV/AIDS programmes.

52. *Chira* is associated with symptoms of gradual weight loss, which in Luoland is attributed to the break with Luo customs and rites. *Witchcraft*, which causes skin disease, stomach disorders or abnormalities in the extremities, is attributed to witches, people with evil intentions motivated by jealousy.

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PART 4
"Social Navigation" and HIV/AIDS

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1. INTRODUCTION

This paper is based on experience gained while conducting an anthropological study for Médecins Sans Frontières-France (MSF-F) in western Kenya's Homa Bay. The Homa Bay area, extending along Lake Victoria, has one of the highest prevalence rates of HIV/AIDS in the country. Active in the area since 1996, MSF initiated a programme in 2001 to deliver free Anti-Retroviral Therapy (ART) in a public health facility. Since then, MSF and the Ministry of Health (MoH) have enrolled more than 17,000 patients in the HIV/AIDS control programme organised at the district hospital and other decentralised sites.

Observing the barriers that local communities face in accessing care, the authors were entrusted with the task of exploring these issues and developing strategic recommendations for future projects. Our distinctive position as researchers and outsiders brought us close to the communities and their personal stories of living with HIV/AIDS. The objective of this paper is *not* to write about the daily struggles of patients, *nor* to reflect on the insufficiency or unavailability of quality care but rather to reflect upon the microcosms within the macrocosms, on agency and tactics that help people to cope not only with the disease, but also with their dependence on medical institutions.

2. A FINE BALANCE?

Visiting patients in their homes allowed us to hear many different stories. A common and surprising trend we saw was that, while patients feel assisted by healthcare providers in terms of access to treatment, they also feel limited when it comes to making decisions about their own lives. This was to some extent corroborated by health workers who, when I talked with them, said that HIV-positive patients are perceived as passive recipients of the programme who should question neither the benefits of treatment nor the medical recommendations. For the patients, however, treatments and their accompanying side effects and rigid medical recommendations often clash with the social reality of their everyday lives and pose some of the most severe challenges.

It is important to remember that as soon as people learn that they are HIV positive, not only do they embark on a life-long dependency on health facilities, but they are also subjected to an invasion of privacy that, to the best of our knowledge, does not occur to such an extent in the treatment of any other disease. Let us review the phrases used regularly in therapeutic education sessions: "prompt and constant consumption of drugs", "balanced diet", "working moderately", "disclosing HIV-positive status to partner(s)", "using family planning" and "practicing safe sex". What then is left to patients to make decisions about? Their compliance with these recommendations is monitored constantly and if they fail to do so, they are pressed into additional therapeutic education sessions to "change their behaviour" and act in accordance with the expectations of the health facilities. So, ultimately it is up to the healthcare providers to judge what is good and what is bad, who will live and who will not - a chilling reality often present in the minds of patients.

The efforts of the public health services to check the spread of HIV, especially in already ravaged communities such as Homa Bay, are indisputable. And it is also indisputable that the main focus of the healthcare providers is to improve and maintain the physical health of their patients. However, other aspects of healthcare are not taken into account in this approach, such as patients' emotional and social well-being. HIV-positive individuals now have long-term aspirations and these involve other people. Therefore, understanding and working with their social networks is crucial as this is one of the main coping strategies for people living with HIV/AIDS. Striking a balance between the demands of care workers and the expectations and personal and social space of patients is the subject of ongoing negotiation.

SOCIAL NAVIGATION

Such negotiations have led patients to develop numerous innovative strategies we call "social navigation". We use this term to refer to the tactics that patients have developed to navigate between adhering to medical recommendations, with as little risk as possible to their lives and related responsibilities (preserving respect and social status, providing financial support to their families, safeguarding their marital relationships from conflict, etc).

My research focused primarily on health seeking behaviours. Therefore, mention of issues of social navigation in interviews was muted. The quotes I present in this paper often provide an indirect insight into the context, and therefore should be read with an open mind. Yet, the examples below demonstrate the need for a broader approach in the way we envisage HIV/AIDS programmes. Needless to say, there is immense potential for further exploration of this topic and the results of such an exploration would provide us with a greater understanding of the realities of people's lives.

ADHERENCE

Taking a drug everyday, twice a day, at exactly the same time, without fail, for the rest of your life; no need to be an expert in behavioural sciences to understand that this is an unrealistic expectation. Adherence to prescriptions was an issue that came up during my interviews, most often in a hesitant, painful tone. Most of the people I interviewed were terrified of being labelled "defaulters" (people who refuse to take drugs either partially or completely). Their observations that "defaulters" ended up dying "before their time" were embedded to such an extent that they were reluctant to even start treatment. Not surprisingly, this fear was also associated with the notion that the health facilities might refuse to provide ARVs to "defaulters".

As per medical protocol, as soon as an individual is diagnosed as HIV-positive, prophylactic treatment should be started. However, many of my interviewees "administered" to themselves for some time before they felt ready to start treatment. This decision, taken in order to avoid becoming "defaulters", gave them the time and the space to accept the overwhelming news of the test result, which led them to re-think their options in life. During this period of "acceptance", they often return to the health facility and get re-tested, making out it was their first test. This is triggered by a worsening of their symptoms or simply because they wish to get confirmation of their HIV-positive status as they are still dealing with intense feelings of denial. The period between the first test and starting treatment sometimes takes years, as demonstrated by the example of a young lady I talked to, who had waited five years. She described her experience:

I have been tested three times (…). I had three (registration) cards, but I used to throw them away. (...). And earlier when I went for the test, I didn't start treatment right away (...).

Because I know somebody should not default. I saw somebody the other side (of the river). She was admitted and than she was given drugs, but she hid them. She didn't take the drugs; and that lady has been already buried, she is already dead. And the second case of somebody defaulting (I know), he was almost dying; but they have started giving him drugs again (...). At first (testing) I was given the yellow card; I remember I was told by the counsellor, not to be worried or stressed even if I was found with it (HIV). And I was asked what will I do (if positive), and I was told (by the counsellor) whatever the results, she would like me to like my work and not to be stressed. And to eat well. So what I did was buy juice, the commercial one. And all the time there was fruit in the house and I would eat (it). But all this time, (I took) no treatment, no drugs. Than I threw the yellow card away. The second time it was also like that… I threw it in the river. And than I decided… I was getting sick, but I would just buy some drugs at the junction here, or somebody would send me some drugs, like malaria, which would be like 170 (shillings)… And than I got sick again… I had joint pains, and I used two blankets to cover myself and it went on just like that. Until the last one (time when sick) when a friend came (to visit) and told me- now you need to go (to get treatment) (HIV-positive woman, Homa Bay, 9/8/2010).

AFFORDABILITY

Eating a "balanced diet" and "working moderately" also cause much pessimism and pondering within the community. The notion of "balanced diet", evoking perhaps the time when this was almost the only area patients could influence to try to prolong their lives, was interpreted as eating expensive food such as meat and fruit unavailable locally. Increased spending on food along with "moderate working" in the context of the fight for survival, were described as a threat to the existence of the community and were openly opposed:

Where we normally go for medication they tell us that we need to eat a balanced diet, we need to work in a temperate manner, not over-stretch; when we get such (information) some people get frustrated: how shall I survive? Now this may make us feel that in few years (from) now our community may be swept (away) (HIV-positive man, Homa Bay, 12/8/2010).

SEX AND PARTNER INTIMACY

Presuming there is no need for discretion in discussing intimate issues, the patient's sex life is talked about openly during therapeutic education sessions: with whom, how and how often (the latter regulated by the number of condoms received during the previous visit). The interviewees often stated that they would take condoms from health workers to avoid further discussion and claim they used them just to ensure the "right" box on the form was ticked. However, they would never consider actually using them. In the Homa Bay community, condoms are closely associated with HIV infection. So practicing "safe sex" is inseparable from unwanted disclosure. Lubricant is also believed to cause infertility

and pain in the lower abdomen. And sometimes using condoms is quite simply not an option, because the patient has decided to have children.

DISCLOSURE

The biggest problem by far is the assumption that HIV-positive individuals are willing and or able to disclose their HIV-positive status to their partners. The risks associated with disclosure are considerable and often unpredictable and can lead to verbal and physical abuse, neglect, withdrawal of financial support, and desertion. One of the interviewees reflected on the complicated nature of talking to his partner:

"Maybe you are not with your wife (but with somebody else). She doesn't know where you are going, where are you walking… You don't discuss... It is difficult to come to her and explain! How do you start? Maybe you were walking badly (misbehaving)... How do you start? (HIV-positive man, Homa Bay, 21/7/2010).

Many of the interviewees did not disclose their HIV positive-status to anyone, including their partners or spouses. Those who did disclose often used a variety of communication strategies that helped them reduce the aforementioned risks. Male interviewees in particular reported that they did not leave any room for discussion with their wives, but used more indirect strategies. They often left their health facility registration card (with the HIV-positive option ticked) in the house or in their clothes on purpose so that their wives would find it when going about household chores like cleaning and washing.

Interviewees from polygamous marriages have more options for social navigation since they can choose to disclose their positive status to just one wife. This removes the pressure from the healthcare providers: ("Yes, I told my partner") and gives them room to manoeuvre regarding their marital affairs. This is the testimony of one of the interviewees who was open with his elder wife about his extramarital partners and HIV infection, but not with the younger one:

"I told the elder wife (about my status), because I had told her earlier "you know that I may bring you this disease (HIV)"! And she is here (in the house) for so long, she cannot run away from home. But if I tell the younger one there is a possibility that she will go away" (HIV positive man, 16/7/2010; Homa Bay).

The same person also suggested a solution to the care workers to enable them to provide the appropriate conditions that would facilitate compliance with the medical recommendations, i.e. full disclosure and use of condoms:

"I have been waiting for these people from the mobile VCT to come, and they ought to come. If they come I will say to my (younger) wife - there is a mobile VCT, go and get tested! So that is what I am voting for… The best way that people could be helped is if you could organize a mobile VCT in a church or a school. You see, the elder wife knows, but the younger one doesn't know about my status. So with the mobile VCT she would know! I cannot break the news to her because she would suspect (that) I am the one who infected her. So then my wife would know her status, I would say - let's now just start treatment and use preventive methods; let's just protect all three of us. And then I could use the condom the way I was taught". (HIV-positive man, Homa Bay, 16/7/2010).

DISTORTING TRANSMISSION KNOWLEDGE

After years of providing information to patients about HIV/AIDS, it is generally believed that the community uses medically-correct terms when discussing related issues. Despite sound knowledge regarding disease transmission, members of the community sometimes choose to attribute their illness to other infectious agents, a decision that helps them avoid conflict within their family. One of my interviewees, a young girl married to a much older man, was quite open about her extramarital partner. She assumed that he was the source of her HIV infection, but was reluctant to discuss it with her husband. When she saw that her husband was falling ill, she chose the following strategy to encourage him to get tested:

"The period when I kept quiet (did not disclose) was maybe five years. When I was tested I didn't tell my husband directly. And when I came (home) with the Plumpy'nut my husband asked (me)- what are those things? And I said - you see, when I went to the supermarket I was getting all these things… And I took these snacks. And even my husband ate it (Plumpy'nut) with me, because I couldn't say it was a medicine. I lied like that… The second time, I was sick again. And I lied that I had a growth in my stomach and that I needed an operation. The third time, I saw that the husband was also getting sick. Than I decided - now it is the time to reveal (the truth). First I told my husband - now, you need to go for a test, an HIV test. And my husband said, "No, I cannot go for an HIV test. You see, I am old… There is no way I would get it (HIV)!" But the husband was getting sick, and I was getting stronger. So I was thinking - I cannot lie to my husband! I need to find a way to tell him (about my status) and ask him to go for the test. So I told him these days, you see, these things (HIV) are not only transmitted through sex… Now you are saying, you are old... It is also transmitted through mosquitoes. Do you remember your son (co-wife's son) was sick? So, the mosquitoes could have sucked his blood and than sucked your blood. Now, this is a major disease. Even mosquitoes have it! So the husband agreed to go for the test (HIV-positive woman, Homa Bay, 9/8/2010).

3. CLOSING REMARKS

These examples are by no means unusual. The patients' experiences illustrate that social navigation is an extremely powerful tool. It is obvious that patients do not only question the advice given to them at health facilities but, regardless of being labelled as uncooperative, they also choose for themselves what they want to put into practice (what is "good" for them). This can be interpreted as undermining the supreme authority of Western medicine, or, serve as a reminder that sometimes it is difficult to decide what is the best solution for an individual, despite the scientific and medical evidence.

It is abundantly clear that the further away medical recommendations are from what is feasible for patients, the greater the non-compliance. In other words, what is the point of having stringent recommendations that nobody adheres to? There is most definitely a need to develop patient-centred care, a holistic approach that considers a patient not only as a person but also as a social being. However, it will be hard to develop care driven by patient needs if the patients themselves are absent from the negotiating table. But that is another question altogether... isn't it?