

Alice Desclaux

Médecin et anthropologue

(2004)

“Equity in Access to AIDS Treatment in Africa: Pitfalls among Achievements.”

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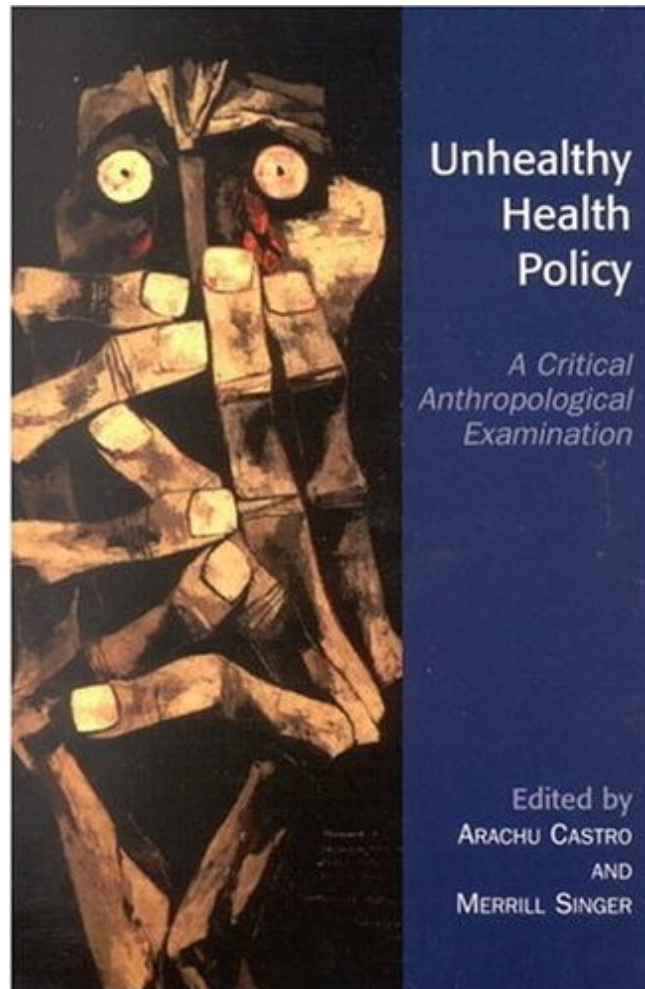


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With more than 30 million people living with HIV in Africa, or 70 percent of the world’s cases, the African continent is facing a major catastrophe. In addition to its associated high human suffering, the HIV/AIDS pandemic represents a critical issue to current public health, especially when considering access to highly active antiretroviral therapy (HAART). In this chapter, I illustrate some of these issues regarding social values underlying health interventions on the basis of ethnographic data from Senegal and comparative analysis with data from neighboring countries.

**The International Issue of Access
to HAART in Africa**

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The last five years have witnessed the effects of globalization and inequalities between high- and low-income countries on access to AIDS treatment in Africa. From 1996, when the effects of HAART were first shown, potent drugs commercialized at high prices in developed countries were first offered at the same—or sometimes higher—prices in African countries, where the average income can be 30 times lower. Welfare protection or health insurance in these countries does not cover HAART; furthermore, the majority of the population is without even this

limited welfare protection. This situation, a new kind of exploitation of underdeveloped countries, was modified by the efforts of activists and public health specialists, and the prices for some antiretrovirals (ARVs) were reduced significantly (Katzenstein, Laga, and Moatti 2003).

In 2000, Access Initiative, managed by the World Health Organization (WHO) and UNAIDS, allowed price reductions under certain conditions in a range of countries. At the same time, the commercialization of generic medicines created a competitive market permitting further price reductions. The struggle of low-income countries for access to medicines, however, is not over; present negotiations for the World Trade Organization's TRIPS agreements ('T Hoen 2003) may open or close the possibility for these countries to buy, sell, or produce the medicines they need ¹ Although low-cost and efficient drugs have been discovered, their price, which is now 30 times cheaper than the prices for triple-combination therapy was four years ago, is still high compared with average incomes in Africa (Moatti et al. 2003). Special regimens needed for some HIV patients, along with medicines used for opportunistic infections or diseases not related to HIV, are not available in these conditions. The availability of low-cost drugs depends partly on political will, which can differ greatly between countries that import generic drugs and those where the government refuses to provide HAART to AIDS patients, and on international measures that shape such issues as external debt and access to multilateral loans. Access to treatment also depends on availability and efficiency of care, from technical skills and means to human resources. The Global Fund to Fight AIDS, Tuberculosis and Malaria is expected to provide the resources to create or enlarge access to comprehensive AIDS care, which includes HAART, and to reduce inequalities in the provision of care in African countries. But much remains to be done; it is presently estimated that in 2003 only 30,000 persons are receiving HAART in sub-Saharan Africa, when the actual need is estimated at about 4 million (Moatti et al. 2003).

Availability and affordability of HAART in Africa depend mainly on political, legal, and economic factors; the control of medicines is the visible part of important present changes in the production of equalities and inequalities regard-

¹ For an update on these issues, see the Access to Medicines Campaign website: www.accessmed-msf.org.

ing access to resources, according to health and trade policies. International health policies implemented in African countries confront not only commercial interests but also differing conceptions concerning the responsibility for the provision of health services and the role of government in public health. Beyond these discrepancies, there are different perceptions of equity and different social constructions of AIDS that should be analyzed in a sociopolitical history of international access to HAART. These changes are also related to the commercialization of health and the political management of diseases, in both developed and low-income countries.

From International to Local Access to Treatment

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If the survival of an African AIDS patient depends on international power relationships and on the legal control of resources, it also depends on the local management of access to care and medicines. Since the publication of international guidelines for HAART implementation in Africa (International AIDS Society 1999), several pilot projects and national programs have begun to provide access to HAART. These programs have been set up by governments through National AIDS Committees under the UNAIDS Initiative (in Uganda and Côte d'Ivoire); with the participation or technical support of UNAIDS (as in Nigeria and Mali); with complementary financial support from international foundations (in Botswana); by local NGOs (as in Burundi and Burkina Faso); by international humanitarian organizations (as in Malawi, South Africa and Tanzania); or by government services and research institutions (as in Cameroon and Senegal). Most programs are managed and executed by a group composed of various representatives from international and local institutions.

Putting medical strategies into practice obliged program promoters to weigh the question of equity in the provision of treatment with limited resources and in conditions contingent on political will and national financial resources. HAART programs provide various categories of terms and conditions for access to treatment. The first programs that were set up, as in Uganda, asked the patients to pay

the total cost of treatment out of pocket (Katabira 1997). Such programs made possible the securing of price reductions, thanks to the provision of medicines through a centrally managed agency, but they were not accessible to the majority of patients. Some programs initiated by humanitarian organizations, such as Médecins sans Frontières (MSF) offered free medicines, for a specified period—from 18 months to five years (MSF 2003). They were inspired by the strategy of “creating a breach” with the aim of demonstrating the feasibility and efficiency of the provision of treatment, thereby inducing governments to take over the programs. National programs tried to combine the goals of accessibility and durability and provided medicines at subsidized rates under various conditions. The diverse modalities of access to programs and the pricing of medicines have resulted in the social and economic selection of patients who can get treatment, and thus of those who cannot.

Publications on pilot projects in sub-Saharan Africa have until now mainly emphasized the feasibility and efficiency of HAART, adherence to treatment, and the risk of creating viral resistance, as these factors were being discussed at the international level (World Health Organization [WHO] 2001; AIDS 2003). HAART programs have also provided observations and experiences about failures and pitfalls in the management of equity that can endanger the health of some categories of population. It is important to describe and analyze these limitations because, for an African AIDS patient, access to HAART can signify survival or imminent death. Moreover, studies and practices in West African countries such as Mali (Imane 2002) and Burkina-Faso (Bronsard 1998) have shown that, lacking a well-run and easily accessible HAART program, patients manage to get ARVs directly from their families living in developed countries, from NGOs and the informal market, or through prescriptions by private practitioners who do not always follow international recommendations for the clinical management of HAART. As HAART requires a high level of adherence and strictly defined prescriptions and follow-ups, these irregular uses of medicines may be not only inefficient but can also lead to adverse side effects or increased risk of viral resistance, jeopardizing the patient’s later ability to recover. Therefore, the mismanagement of equity in the provision of HAART results in the loss of opportunities to improve health and exposes a number of patients to iatrogenic conditions.

This anthropological analysis provides insights into the categorization of population groups by the health system and the subsequent medical control of the "social body" in Senegal. It also provides insights into concepts underlying equity and its management that are rooted in the culture of international health or in contemporary African culture. The perceptions and practices pertaining to the equity of programs at the local level stem from the dialectics between these two cultural backgrounds and from the power relationships and negotiations or confrontations among the different institutions mentioned above.

This analysis will be centered on the Initiative Sénégalaise d'Accès aux ARV (or Senegalese Initiative for Access to ARVs, or ISAARV), launched in 1998 in Dakar by the National AIDS Committee under the authority of the Ministry of Health. This pilot project was the first to be entirely designed and set up by a national team of health professionals, on a budget provided by the government, and at a time when most international institutions were reticent about access to HAART in Africa. The pilot project was organized on an empirical basis, and its effects were evaluated by epidemiologists and social scientists between 1998 and 2001, leading to a redefinition of the scope and means for provision of treatment. Research in medical anthropology was conducted, mainly among patients undergoing treatment, to discern the social effects of the program (Desclaux, Lanièce, Ndoye, and Taverne 2002).²

The results of these studies were, until 2002, regularly discussed with the team managing the program. In Dakar, the program was partly revised based on results from epidemiological and anthropological studies, and has evolved according to local changes and reductions in the international prices of drugs. However, the features and results of ISAARV must be carefully considered from a critical point of view, since this program has been considered as a model for the establishment of other national programs in West and Central Africa, in spite of its limitations, which will be described below.

² For details on the research program, see the acknowledgments listed above.

The ISAARV Program

The Establishment of a Pilot Project

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ISAARV was the first pilot project of its kind and its promoters had to face strategic choices, confronted as they were by uncertainties as to the feasibility, efficacy, and acceptability of antiretroviral therapies, as well as by the prevailing material and financial constraints. The project was designed to be integrated in three hospital services. The health professionals responsible for the execution of the program (physicians, biologists, virologists, pharmacists, and social workers) were invited to participate in its definition and planning. They set up a management board composed of four committees in charge of program planning, patients' inclusion, and follow-up (Eligibility Committee); therapeutic and medical decisions (Medical Committee); nonmedical aspects and social research (Welfare Committee); and drug management (Pharmaceutical Committee) (Desclaux et al. 2003).

ISAARV was designed to be accessible to all persons requiring treatment with antiretroviral drugs, regardless of their nationality or socioeconomic status, provided they were residents in Senegal. Drugs were financed both by the government and by the patient—the amount to be paid by the patient was calculated according to his or her personal resources. Patients selected by a physician on the basis of immunovirologic and clinical criteria underwent an "inclusion" interview by a social worker, with the aim of assessing the patient's economic resources and social support network, identifying other HIV-infected persons in the household, and ensuring that the patient had correctly understood the constraints of three-drug regimens. The results of the survey were discussed by the Eligibility Committee, which endorsed the decision to provide treatment and determined the cost (including cost of medicine) to be borne by the patient. Personal, household, and family incomes and expenses were considered in the determination of this

amount. Children, health professionals, and active members of self-help groups for people living with AIDS (PLWA) were exempted from financial participation.

When the program was launched in 1998, the price for a triple-combination therapy was about 300,000 FCFA (US\$ 457)³ per month: the establishment of a unique provision system by the Pharmaceutical Committee and the Ministry of Health's National Procurement Pharmacy had decreased by half the price of drugs in Senegal, drugs that had been previously available only through private drug sellers.

Achievements of the Program

The number of patients included in the program slowly increased during the pilot period, from 60 in April 1999 to 300 in November 2001 to 1,051 in March 2003. Clinical outcomes such as viral resistance and adherence were similar to those observed in developed countries (Laurent et al. 2002). The level of viral resistance was not greater than in developed countries, which could be explained by the use of regimens based mainly on triple combination therapy, a well-managed patient follow-up, and an adequately accessible program (Touré-Kane Ndeye et al. 2002). The level of adherence was high, similar to levels obtained in industrialized countries: average adherence among 158 patients during a 24-month study period (November 1999 to October 2000) was 91 percent (Lanièce et al. 2003). Factors that may explain this good adherence include the experimental nature of the program, recent inclusion in a small cohort of patients, and the fact that most of the patients had never previously received ARVs. Patients were highly motivated because they were symptomatic at the time of their inclusion in the program and they considered getting treatment a privilege. Patients' adherence was supported mainly through counseling by the pharmacist. Two main factors were found to reduce adherence: the type of drug combination (as in industrialized countries, simplified treatment regimens, especially with nonnucleoside reverse transcriptase inhibitors (NNRTI), appear to be better managed and better accepted) and the cost of treatment. Overall adherence was best among patients receiving free treatment.

³ US\$1 = 640 FCFA.

Social Impact of Equity Management in ISAARV

Financial difficulties soon appeared to be the main barrier for patients' inclusion and adherence, both in questionnaire inquiries and qualitative surveys among patients and in the daily management of the program. Difficulties regarding access to treatment had three kinds of consequences: noninclusion of patients in the program, adherence problems, and social hardship of included patients due to payments requested as family support.

Noninclusions

During the first year, there were seven rates for the same triple-combination treatment (Table 7.1), and the minimum monthly cost for patients (subsidized at 93.5 percent) was 21,000 FCFA (US\$28), while the legal minimum wage in Senegal at that time was 36,250 FCFA (US\$48.3).

<tab7.1>

Although low compared with the cost of drugs paid by the Ministry of Health, this amount was an obstacle for many patients; in 2001, 30 percent of ISAARV patients had no income and two-thirds of them lived below the poverty line. Patients for whom antiretroviral treatment was medically indicated, but who did not meet economic criteria, were excluded from the selection process, either before or after their financial needs. Moreover, to avoid raising false hopes, medical doctors generally conducted an informal selection prior to the social survey on the basis of the patients' presumed ability to pay.

Nonincluded patients have remained invisible, and their number cannot be estimated. The lack of material and organizational means for the follow-up of patients restricted the capacity of health services to keep information about them, information that could have led to their inclusion when conditions for access changed. Data from qualitative interviews show that noninclusion in the program was felt by some patients as an exclusion, leading them to stop seeking treatment in ISAARV services. Instead, they turned to other health professionals or to traditional practitioners—some of whom are available in the same hospital services—

to experiment with folk medicines. Some patients, often with the help of health professionals, found strategies to get access to treatment, most often by joining PLWA self-support groups. For other patients, the attitudes of health professionals based on denial, silence, and the conscious or unconscious restriction of access to preinclusion (for instance, through limiting access to HIV testing) act as a kind of regulation and can be viewed as the "shadowy side" of the program.

Adherence Problems

The analysis of factors influencing adherence in Senegal showed that adherence among patients receiving the same treatment decreased as the amount of their financial participation increased (Lanièce et al. 2003). This trend was noted during the first year of the study and, to a lesser extent, during the second year. Just as treatment interruptions due to financial problems have been reported in other African settings (Delaunay, Vidal, Msellati, and Moatti 2001), financial obstacles led to prolonged discontinuations of treatment in ISAARV until, following a decision of the Eligibility Committee, patient fees were reduced. The effect of such interruptions on patients' health are deleterious, since a very high level of adherence is required by HAART (more than 90 percent of prescribed intakes) to avoid treatment failures or emergence of viral resistance. In some cases, the economic difficulties of the patients were observed soon after enrollment. After a few months, patients could recognize that they had undertaken costs that were too high for their income, especially when they had to face other unexpected expenses or when the family members supporting them had other priorities. Besides poverty, precariousness is another characteristic of the household economy in African countries, which appears as a structural limitation to paying for the cost of treatment. Moreover, in urban settings, where households are more often composed of nuclear than of extended families, individuals have fewer opportunities to receive family support (Mary 1997).

For patients who have overcome the acceptance stage of treatment and adapted the management of their personal resources to the monthly HAART payments, problems might arise later when they have lost the social status lent by the "sick role." When the physical stigma of the disease disappears under

HAART, the patient is expected to return the help received from his family, who often does not understand why the patient must still pay for treatment or why he or she does not face his or her social obligations again, such as sharing family expenses. These economic difficulties lead to the exclusion of some patients during the first year of ISAARV.

Compensations for Family Support

Many patients had to solicit help from their families to meet the monthly cost of their medicines and were often supported by relatives or friends, who made monthly contributions. Asking help from family members obliged patients to reveal their HIV status in a society where HIV/AIDS is still a stigmatizing disease. Disclosure of status had different consequences, leading some patients to leave their families and others to reinforce links with some family members. Disclosure and the request for financial help in many cases reactivated previous family conflicts. Patients dependent on the financial help of the family had to obey family requests; they were often asked to conform to social norms or to respect religious prescriptions, as if obedience were to compensate for economic support.

In other cases, the question of intrahousehold resource allocation led patients to unavoidable dilemmas, such as when the costs for treatment make it impossible for a household to meet other priorities, such as the illness of a family member. In many cases, these situations jeopardized the patients' health; in most cases, they created anxiety and additional social suffering for AIDS patients.

Analyses of a System

Limitations of a System Aiming at Equity

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It is difficult to assess whether the sliding fee set up in ISAARV helped to treat more patients than a "low cost for all" scheme. The overall recovery rate was low: it was estimated at 12 percent of the costs for medicines during the first year. The sliding fee appeared to be time consuming and resource consuming, inaccurate, and inefficient. Due to difficulties in assessing the resources available to an individual or a household in a social context in which most active adults have no declared salary and hold irregular or casual jobs, financial assessments were lengthy, difficult to conduct, and imprecise. Patients felt these inquiries were intrusive and presented a risk of breach of confidentiality. Long discussions of cases in the Eligibility Committee often reflected subjective perceptions or expected social values. Many patients, in the meantime, had to apply for a price reduction because they could not come up with the fee requested from them. In 2000, an experiment was begun using "scores" based on simplified criteria in order to shorten the financial assessments, and the number of price categories was reduced. However, this simplification could not meet the increasing number of inclusions. The "scoring" was abandoned, and the multileveled price scale was progressively replaced by a two-rate system.

Meanwhile, other studies were undertaken to discover the magnitude of the patients' economic burden. Besides payment for medicines, patients included in ISAARV had to pay direct medical costs (including costs of medical visits, biological and radiological examinations, hospitalization, travel, and medicines, but excluding the purchase of ARV) of an average of 5,200 FCFA (US\$ 8.10) per month (Canestri et al. 2002). This amount was far beyond the capacities of the Senegalese population: in Dakar, 83 percent of the population have no welfare protection. Moreover, people who do have protection are reluctant to use it because they fear confidentiality will be breached.

After the November 2000 Price Reductions

The patients' contributions to the cost of their treatment evolved according to the prices imposed by pharmaceutical companies. Prices fell after November 2000, and a government subsidy of 100 percent was introduced. Following the reduction of antiretroviral drug prices early in the second year, the average contribution made by patients already on treatment was cut fourfold, and minimum participation was cancelled. The sharp decrease in the cost that patients had to pay contributed significantly to the improvement in adherence during the second year (90 percent in year 2 versus 83 percent in year 1). When interviewed, patients reported that financial difficulties were the leading cause of treatment interruption in the first year, but only the fifth cause in the second year.

Low Prices and Free Treatment as the Final Choice

The ISAARV pilot project gave an opportunity to quantify the limits and failures of an ARV access program that required payment by patients. It also provided an estimate of prices that patients can bear and of the amount needed to support patient access to ARV, in addition to the cost of drugs. Following an evaluation of the program and the reduction of international prices for medicines, ISAARV changed its method of pricing to reach more patients. In November 2002, to provide access to patients in need of treatment, to ensure their adherence, and to mitigate onerous inclusion processes, 95 percent of the patients included in ISAARV were provided treatment free of charge, and 5 percent were provided treatment for a payment of 5,000 FCFA (US\$7.80).

Discussion

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Multilevel pricing for medicines can be viewed as an economic experiment that will survive neither the difficulties met in its application in Senegal nor the evaluation of the process and tools used in ISAARV. Other as yet unevaluated schemes aimed at equity in access to HAART are still in use.

Selection Based on Social Criteria

In most African countries that have implemented comprehensive AIDS programs, pricing includes a "standard" price for usual patients and waivers or exemptions for patients belonging to different categories and groups. In Mali, for instance, a multilevel price scale has been planned, combined with a fee exemption for active members of PLWA self-help groups and for health professionals. However, until the implementation of this system, usual patients are asked to pay 45,000 FCFA (US\$70.30) per month—which represents a 50 percent subsidy for triple-combination therapy at local cost. In Côte d'Ivoire, initial pricing considered "priority categories" that included women who had previously participated in clinical trials for the prevention of mother-to-child transmission, members of PLWA organizations, and, more recently, public-sector health professionals—who had to pay 10,000 FCFA (US\$15.60) per month for triple-combination therapy in 1999, which represents a 95 percent subsidy in this country. In addition, those considered poor (under unspecified criteria) who could obtain a partial waiver were asked to pay 80,000 FCFA (US\$125), which represented a 60 percent subsidy (Delaunay et al. 2001) until April 2001, when this fee was reduced to 25,000 FCFA (US\$39.10) for people with several dependants. In Burkina-Faso, the Ambulatory Treatment Center, which provides HAART in Ouagadougou, has established four fees: free access to orphans; 5,000 FCFA (US\$7.80) for pregnant women, health professionals, the poor, students, and school children; 10,000 FCFA (US\$15.60) for government employees; and 20,000 FCFA (US\$31.20) for businessmen and traders (Alzouma 2002). No published information is available as to how patients are categorized in practice.

The variety of criteria in neighboring countries with similar social and economic contexts is surprising. Moreover, the analysis of the use of categorizations and social criteria for ISAARV patients showed that they did not correspond to clear-cut definitions and were applied in a rather arbitrary manner. The choice of exempted categories is based on various logics (social productivity, level of income and inability to pay, merit, deontology) embedded in social values that are expressed differently according to context. In some cases, such as Mali, where the minimum cost for most patients is nearly twice the minimum wage, not being classified in such categories may lead to exclusion from HAART programs.

Recent studies in the context of primary health care or hospital care in different settings have shown that exemptions or waivers for treatment or hospital charges were seldom offered to patients who would have needed them and had the right to obtain them (Meng, Sun, and Hearst 2002; Kivumbi and Kintu 2002; Paphassarang, Philavong, Boupha, and Blas 2002). The Bamako Initiative policy considered exemptions and waivers as a way to achieve equity, but evaluations of its implementation in West Africa show that measures for the poor were foreseen, but still not in effect ten years after its introduction (Ridde 2003). Several economic studies of cost-recovery policy in West Africa conclude that neither governments nor local health professionals are really interested in translating the rhetoric of equity into practice devoted to health access for the poor (Dumoulin and Kaddar 1993 ; Jaffré and Olivier de Sardan 2003). These observations challenge the capacity of "positive discrimination" based on social criteria to ensure equity in access to HAART.

Low Prices or Free Treatment for All Patients

Since the use of social criteria for achieving equity is limited, the best proposition might be to provide low-cost or fully subsidized treatments. Numerous ethical and social arguments favor the free provision of HAART in countries that are already severely affected by AIDS (Farmer et al. 2001). The experience of ISAARV has shown that there are also medical and technical arguments to defend this proposition (Taverne, Lanièce, and Desclaux 2002). As a crippling chronic disease if untreated, AIDS reduces the ability of patients to maintain their financial autonomy. The economic situation in African countries, the impact of AIDS on household budgets, and the cost of treatment regimens for opportunistic infections mean that most patients, despite returning to paid work while on treatment, still cannot afford their drugs. Therefore, AIDS should be considered a "social disease," which means, in health care systems of many African countries, that its treatment should be provided free as it is for tuberculosis or leprosy.

Multilevel payment systems or exemptions and waivers may appear as alternatives, but they are limited solutions (Vinard 2002), since they leave many patients untreated who will remain unknown and unaccounted for in program eva-

uations. The risk of increasing inequalities between the rich and the poor, or between people from different, unclearly defined categories, can only be removed by granting subsidies covering the entire cost of treatment to a large proportion of the patients' population. In Dakar, the provision of heavily subsidized treatment had other advantages: it protected patients from getting irrational treatment regimens. It also contributed to lower demand for antiretroviral drugs on the informal market, and therefore reduced the risk of viral resistance.

Implications

Paying for Treatment: Meaningful for Whom?

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The issue of economic access to HAART has questioned the necessity and meaning of patients' user fees. In addition to cost-recovery needs to sustain programs, three main reasons for the implementation of user fees are given by public health professionals involved in West African HAART programs. First, many professionals and some of their colleagues from developed countries argue that patients would consider free medicines to be worthless, leading to low adherence (Desclaux 2001). Second, some consider that receiving free treatment might be humiliating for patients (Desclaux 2001). Third, it has been said that "traditional African solidarity" can help individuals to bear the economic burden of treatment (Groupe de Gorée 2001). This discourse is more than an adaptation to necessity; it promotes payment as having its own value, as leading patients to a better adherence and bringing health professionals to show more respect to patients, as well as obliging families to increase their support of members affected by AIDS.

These three dimensions of the meaning of payment are challenged by the experience and analyses of ISAARV. Our experience in Dakar shows that the assertion that paying drugs out of pocket leads to increased adherence is not supported by evidence. The provision of free ARVs can be felt as an insult to one's dignity only if it is seen as an act of condescending charity, rather than as a right to health and a social imperative. Family solidarity is active in Dakar, but it is limited by

poverty and insecurity, and requesting payment from patients creates an additional burden. In African societies, where AIDS is stigmatized, support from families is not to be taken for granted. Moreover, it may seem paradoxical that the fully subsidized provision of ARVs by governments or welfare systems in Europe and other wealthy countries does not give rise to such comments; in those countries, access to ARVs is seen as a social and human right, and patients do not feel humiliated when they get them free of charge.

Since these discourses are refuted by local experience, as seen in Dakar, their origin should be sought in the medical culture of public health in Africa, in the context of World Bank policies, the Bamako Initiative, and their subsequent interpretations. Some scientists consider that the Bamako Initiative, which was supposed to ameliorate health services by setting up cost recovery and financial autonomy (WHO 1988) and which was only partially implemented, has promoted neoliberal measures, pleading for the transfer to the community of financial responsibilities previously met by the health system (Turshen 1999). The local plea for user fees, regardless of the reason given, should be analyzed as the expression of politically constructed values. We may wonder if the inability of public health professionals and patients from low-income countries to request free provision of medicines cannot be considered as a submission to an international order of values in which "the poor" should not request more than what is acceptable to the rich.

Double Payment for HIV Patients?

As AIDS patients are requested to pay for ARVs, they are also requested to disclose their status to raise support from their families or to obtain waivers through PLWA self-help organizations. In Mali, fee waivers are granted to "active" members of self-help groups. "Active" status may be defined differently according to each group, but all patients who have publicly admitted their seropositivity, for example during TV or radio programs, are considered "active," as are persons who participate in preventive and educational activities. The declared logic for such favorable treatment is the contribution, through public disclosure, to the destigmatization of AIDS through the "trivialization" of seropositivity, which is encouraged by international agencies such as UNDP and UNAIDS. Al-

though the role of PLWAs in increasing AIDS awareness has been shown in African countries and elsewhere (UNAIDS 2000), evidence is needed to support that public disclosure of HIV status for all AIDS patients is more efficient for advocacy than protection of confidentiality. People whose autonomy is not protected by their social status may suffer from the adverse reactions of family members or coworkers to the disclosure of their seropositivity. Their dependants may also pay a price for this public disclosure, such as subsequently suffering themselves from stigma. Then, we may wonder if public disclosure is not a "second payment" to access treatment, and a form of confession of having a disease still frowned upon. Such a symbolic logic may not be supported by international agencies, but it does correspond to old and deeply rooted perceptions of disease as a retribution for misconduct that can be cured through penitence and sacrifice. Disclosure as an alternative to financial contribution is not an accepted form of payment for drugs to treat other diseases, and we may wonder if this "double payment" is not an indirect form of ostracism toward AIDS patients.

Social Impact of "Community-Based" Management of Equity?

In countries such as Mali and Côte d'Ivoire, where active membership in PLWA self-help organizations provides waivers or free treatment, many AIDS patients turned to these groups when requesting access to HAART programs. This situation has led to social changes for these associations, strengthening their position vis-à-vis health services, opening opportunities to reinforce internal distribution of power through the choice of criteria for the election of "active" members that will receive access to free or highly subsidized treatment, or creating new power relations between older and newer members. This evolution might reinforce the identity of PLWA among AIDS patients and improve the chances of self-help groups or individuals belonging to these groups to gain better social acceptance in the health system or in their communities. It might also have other consequences such as conflicts between individual and collective strategies, or legitimacy conflicts between PLWA groups.

The social changes resulting from the delegation of the management of equity to community-based organizations are not well-known, are difficult to anticipate, and depend on local situations. Giving more power to the civil sector in health programs has been promoted by international organizations such as UNAIDS and UNDP and by private, bilateral, and multilateral donors, and is at the heart of many development policies widely inspired by neoliberalism. The consequences of this strategy regarding equity in access to HAART remain to be analyzed.

CONCLUSION

The withdrawal from the health system of patients who cannot afford user fees, which are often beyond the reach of the majority of the population in low-income countries, is not specific to AIDS: this is commonplace for diseases such as cancer, renal insufficiency, or even high blood pressure. Even in cases of frequent diseases that require simple treatment regimens, it has been shown that in the last decade increases in out-of-pocket health costs have driven some families into poverty and increased the hardship of those who are already poor (Kim, Millen, Irwin, and Gershman 2000); this has been termed "the medical poverty trap" (Whitehead, Dahlgren, and Evans 2001). Criticism by public health specialists based on extensive field research and experience has concluded that privatization policies in health care are regressive regarding equity, mainly because sharing the financial burden of the disease is reduced and payment falls more directly on the sick than on healthy individuals (Ridde 2003). It has been shown that strategies such as the Bamako Initiative were based more on ideological orientations than on evidence of its efficacy. Data increasingly show that several aspects of this strategy are prejudicial to the poor. Although the World Bank has taken some of the criticism into consideration, it has not yet been translated into practice.

The high number of people living with HIV/AIDS in sub-Saharan Africa and needing access to HAART emphasizes the importance of social responsibility at the international level when addressing issues of equity in access to comprehensive AIDS care. So far, the economic burden of AIDS in Africa has been mainly shifted to governments, households, and nongovernmental organizations, sparing the private sector (Rosen and Simon 2003); this is also the case for the provision

of ARVs. Requesting partnerships between governments, the private sector, and NGOs to support national programs, the Global Fund to Fight AIDS, Tuberculosis and Malaria provides an opportunity for a change in resource allocation that might alleviate the burden on households.

Data from pilot projects showing the achievements, limitations, and pitfalls of different systems of access to AIDS care are becoming increasingly available (AIDS 2003). To meet the equity objectives, policy makers should move beyond values resulting from a decade of public health emphasis on user fees and from an international order based on double standards according to the ability to pay. They also should be cautious about strategies delegating management of equity to community-based organizations. Medical anthropological research on values underlying health and public policies and on the social consequences of choices in the delivery of AIDS care is more than ever necessary, at the local and at the international level.

NOTES

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END

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