Health and Human Rights

They Call It "Patient Selection" in Khayelitsha: The Experience of Médecins Sans Frontières-South Africa in Enrolling Patients to Receive Antiretroviral Treatment for HIV/AIDS

RENÉE C. FOX and ERIC GOEMAERE

The Médecins Sans Frontières Khayelitsha Project

In 1999, Médecins Sans Frontières (MSF) set out to explore and demonstrate the feasibility of preventing and treating HIV/AIDS in a so-called resource-poor, economically and so-cially disadvantaged setting. The first MSF mission to incorporate antiretroviral (ARV) treatment into its HIV-AIDS-oriented medical program was undertaken in Bangkok. The second project was launched in Khayelitsha where MSF has been providing ARV

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treatment for persons with HIV/AIDS since May 2001.1 Khayelitsha is an enclave of some 500,000 inhabitants, most of whom live in corrugated-iron shacks, without running water or electricity. Unemployment is extremely high; crime and violence (including robbery, domestic violence, rape, and murder) are rampant. The general prevalence of HIV/AIDS is 26%, measured among pregnant women. The tuberculosis incidence rate is one of the world's highest for open-space sites (1,380/100,000). Unsurprisingly, TB/HIV coinfection is very high too: 63% of those with TB are also infected with HIV.

These data reflect the epidemic proportions of HIV/AIDS in South Africa. Out of a national population of some 45.5 million people, as many as 5.2 million are currently HIV-positive—more than in any other country worldwide. In 2004, 311,000 persons died of HIV/AIDS-related diseases (almost 900 every day).

The treatment component of the Khayelitsha project is centered around the deployment of first-line, high-acting, antiretroviral drugs therapy (HAART), in a three-drug regimen of Stavudine or AZT, Lamivudine, and Nevirapine or, in the case of persons with concomitant tuberculosis,

Efavirenz. Mainly high-quality, relatively low-cost, generic forms of these drugs are used.² The aim of this triple therapy is to arrest the progression of the disease by keeping the viral load low enough to enable the symptoms of this ultimately fatal disease to be managed. Thus, the persons afflicted can meet the demands of everyday living for as long as possible, and their survival time will be extended. Once the treatment is begun, it requires the faithful, continuous taking of the medications for the rest of a patient's life. The daily pill burden varies according to the regimen, but in a country like South Africa, where fixed dose combinations are not yet available, it involves taking four to seven pills a day. If the individual with AIDS fails to take the drug regularly, the HIV virus, which "learns quickly," will multiply rapidly, develop ways of escaping the treatment, and the patient will swiftly succumb to the disease. If such a person is not practicing "safe sex," there is the public health danger that he/ she may transmit a drug-resistant form of the virus to others.

Eight thousand persons with HIV/AIDS are now treated in the three clinics established in the three community centers of Khayelitsha. Two thousand of these patients are currently receiving ARV treatment, including 130 children. Another 500–600 patients are being worked up to receive ARV treatment, as they qualify for it. The majority of the 6,000 patients, who are not yet eligible to be put on the waiting list or to receive ARV, are followed at longer intervals, for prophylaxis and treatment of opportunistic infections.

Each clinic has two physicians, three nurses, and three counselors who form the clinic's team. Physicians deal primarily with patients in advanced clinical stages of the disease who are not yet receiving ARV medication. Because these individuals are desper-

ately ill and susceptible to severe, recurrent, opportunistic infections, it is felt that the expertise of a physician is needed to handle the intricate, lifethreatening complications that their situation presents. Nurses take responsibility for most of the continuing and follow-up care of both ARV and non-ARV patients, whereas physicians manage the serious side effects of the ARV medications and problems of resistance to the drugs that may occur. The counselors' work focuses mainly on preparing patients for ARV treatment, furthering their understanding of the disease and its treatment, promoting their adherence to the drug regimen, and involving them in support groups.

One of the project's most distinctive characteristics is that, without becoming politicized, it has been collaborating with the Treatment Action Campaign (TAC). TAC is an HIV/ AIDS-dedicated, South African civic organization that developed from the antiapartheid movement. The organization has led a powerful struggle to raise local and national awareness about the HIV/AIDS epidemic, to advance openness about it, to reduce the stigma associated with it, to implement educational programs to lower its incidence, to prevent its transmission, to develop "treatment literacy," and to put the Government under pressure to enact a national HIV/AIDS prevention and treatment program that includes ARV treatment for all those in South Africa who need it.

The "Patient Selection" Process and Its Evolution

A particularly difficult and disturbing problem that the staff at the Khayelitsha project has encountered is how to decide who will be started on ARV treatment and when. To find criteria that are both medically sound and ethically just is a challenge of humbling proportions. The fact that MSF is a movement that operates within a culture of inquiry and debate has contributed to the staff's continuous concern about what they refer to as the problem of "patient selection."

In the earliest days of the Khayelitsha project, only 180 patients could be supplied with ARV treatment due to a lack of funds. During this time, staff used a "priority scoring system," which they experienced as a dismaying process of drastic selection. Priority scores were rapidly abandoned at the end of 2003 when MSF committed sufficient funds to the project to enable the treatment of 400 persons.³ It was at this juncture that the project established a so-called selection committee, composed of clinical staff members. The committee was centrally run, met once a month, and strove to attain impartiality in the decisions it made. This was meant to be achieved through norms of strict anonymity and transparency and the participation of a large number of community representatives in its meetings. Their decisions to start patients on ARV treatment were based on a mixture of medical, social, and so-called adherence criteria. The latter consisted of indicators suggesting that patients provided with ARV treatment would take the medication faithfully and regularly.

On November 19, 2003, the Department of Health of the South African government approved a long-awaited Operational Plan for Comprehensive Treatment and Care for HIV and AIDS that set into motion a political process to progressively make free ARV medication available to all citizens of the country with HIV/AIDS.⁴ This national rollout unlocked international funding, with the result that since July 1, 2004, 80% of Khayelitsha's ARV drug supply comes from the Global Fund to Fight AIDS, Tuberculosis and Malaria and only 20% from MSF, and

the majority of the staff is paid by the Provincial Department of Health of the Western Cape. As a consequence, lack of financial resources is no longer the bottleneck for the Khayelitsha project. Sufficient funds are available to enroll as many persons with HIV/AIDS in the township for ARV treatment as the program deems it can handle. In this regard, the project is moving closer to assuring universal coverage in Khayelitsha financially, and in the course of 2005, it is hoped that 100% of the pediatric and 50% of the adult needs for treatment can be met.

At present, it is shortage of staff rather than restrictions in funding that limits the number of patients to be enrolled for treatment. Although public health salaries in South Africa are high enough to attract medical and nursing personnel from neighboring countries, a sizable number of South African physicians and nurses have found professional positions in the United Kingdom, Canada, Australia, and the United States, where they can earn higher incomes. At the same time, the HIV virus is also contributing to the dearth of available health professionals, many of whom have been infected with AIDS.5

This deterrent notwithstanding, the significant increase in funding has enabled Khayelitsha to considerably expand its patient enrollment (from an average of 32 new patients per month in 2003 to 97.5 a month in 2004), leading to an alteration of the selection procedure. Instead of one central selection committee for the entire Khayelitsha site, individual selection committees for each of the three HIV clinics have been established. These committees meet fortnightly, are mainly composed of and managed by clinical staff, and include one patient in its membership who is defined as an "external witness."

At the meetings of the selection committees, a clinical nurse presents patient-candidates who are regarded by staff as the potential recipients of ARV treatment with the most urgent need of receiving it. A set of medical, social, and adherence criteria are used to arrive at this evaluation. The medical criteria are as follows:

- The patient must have undergone two tests that confirm his/her HIV serostatus.
- He or she should be in what the World Health Organization designates as stage 4 of the disease, or in stages 1, 2, or 3, if the patient's CD4 count is <200 cells/mm³.
- When possible, TB treatment and ARV are not initiated concomitantly in patients with <200 CD4.
 Rather, ARV treatment is delayed until 2 months after the TB intensive treatment phase.

The social criteria include the following:

- A record of regular clinic attendance by the patient (at least four scheduled visits to the HIV clinic).
- The patient's residence in Khayelitsha and commitment not to move away from the township for at least 6 months. (If the patient does not live permanently in Khayelitsha, the possibility now exists for arrangements to be made, before initiating therapy, to transfer her/ him at the end of the 6-month period, with a 1-month supply of medication, to 1 of the 28 ARV treatment centers in the Western Cape or 1 of the 7 in the Eastern Cape that have been opened since 2004. However this is only feasible if such a treatment center is physically close enough to the patient's home to ensure continuing care.)

- The patient's commitment to longterm ARV treatment and to safe sex practices ("condomizing," or abstaining from sexual relations).
- The patient's willingness to disclose his/her HIV status to a person in their confidence (older than 18 years of age), who agrees to act as the patient's treatment assistant.
- The patient's readiness to attend a support group for persons on ARV treatment at least once a month during the first year of treatment.
- Alcohol or other substance abuse and untreated active depression are regarded as social contraindications for initiating ARV treatment.

The main adherence criteria consist of the following:

- The patient's presentation on time to the last four medical consultations ("on time" is liberally defined as on the day of the scheduled clinic visit).
- The patient's attendance at a minimum of three intensive counseling sessions.
- Agreement to a preliminary home visit by a counselor or nurse to discuss the treatment with the patient and the treatment assistant, if there is uncertainty concerning his/her ability to meet any of the criteria, or family problems that might impede their fulfillment.⁶

In principle, fulfillment of *all* medical, social, and adherence criteria is required for beginning ARV treatment. The primary data reported by the clinical nurse at selection committee meetings are medically relevant facts concerning the patients under consideration: their date of birth, gender, the date when they were first seen in

the clinic and diagnosed as HIV positive, the number of visits they have made to the clinic, their CD4 count, the stage of their disease, what opportunistic infections they have had, and whether they have a concomitant diagnosis of tuberculosis. The physician (or physicians) participating in the meetings focus on the medical (biological and clinical) criteria and on what is euphemistically called patient "fitness" to begin ARV treatment. The latter chiefly refers to the program's "inclination" to exclude patients with active tuberculosis, because of the high probability that after the initiation of ARV treatment such patients will develop an immune reconstitution that will cause their clinical status to worsen. Counselors are responsible and accountable for long-term patient adherence, and they have the final word in the decisions regarding the start of the treatment. On average, some 30 to 40 patient-candidates are reviewed by each clinic each month.

Reluctance to Refuse Anyone for ARV Treatment

Despite the elaborate, well-thoughtout set of criteria meant to guide the selection committees' decisions, the most striking feature of their deliberations is the inward pressure they feel to accept patients for treatment. Even when a patient does not meet certain of the social and adherence criteria such as readiness to use condoms, punctual keeping of clinic appointments, regular participation in a support group, or disclosure of HIV/ AIDS status—the inclination is still to admit him or her into the ARV program. The staff assumes that patients can be helped to fulfill-both before and after the initiation of treatmentany conditions with the help of counselors and fellow patients. "Preparing" patients for treatment, as this process

is called, has become so predominant that, with humor-tinged seriousness, some staff members have suggested that the "selection" committees ought to be renamed "patient readiness" committees.

"We never definitely give a 'no' to any patient for ARV," one of the MSF physicians noted. "This is felt to be unethical. We just say, 'Not ready.'" The closest they come to turning a patient down, he contended, was illustrated by a case in which the period of "temporary refusal of ARV treatment" was so prolonged that "when we finally gave the green light [to start it], it was too late":

X. was a 26-year-old woman, with HIV/AIDS, who was living alone with her 6-year-old daughter. She had developed pulmonary tuberculosis, and was not able to adhere to the course of treatment for it. The decision was made to send her to the local hospice run by the Order of Mother Teresa's Sisters (the Missionaries of Charity), where she could receive supervised TB therapy. She improved dramatically under their care. However, she insisted on being discharged from the hospice before the Khayelitsha team could start her on ARV medications and then disappeared from their view. Three months later, she returned to Khayelitsha and was seen in one of the HIV/AIDS clinics, in an emaciated state, with a very large ulcerated herpes zoster, and in urgent need of ARV treatment. Because of her previous record of irregularity in keeping appointments and her nonadherence to TB therapy, it was decided that her ARV treatment would have to be carried out under supervision and that she should be readmitted to the hospice for this purpose. It took her a long while to accept these conditions, and when she finally did, she was in the terminal stage of HIV/AIDS. She was immediately started on ARV treatment, but she died in the hospice a few weeks later.

The Khayelitsha team finds it difficult to accept the possibility that certain patients may never reach or maintain the "preparedness" level to receive ARV treatment required by the social and adherence criteria, despite all the coaching and support they receive. As the following example shows, they find it hard to accept that ARV treatment should not be started or, if a patient is already receiving the therapy, that it should be withdrawn.

L., a 32-year-old male patient, was among the first to be enrolled in the Khayelitsha ARV program. Although the selection committee was aware that he was violent toward his girlfriend and that he abused alcohol, they believed that he would be able to turn his life around and stabilize it. Their confidence in his capacity was based on their admiration for his dedicated involvement in the Treatment Action Campaign (TAC). L. had organized a TAC branch close to his home, and worked hard to promote access to treatment for HIV/AIDS. However, he was never able to find regular paid employment.

Shortly after starting ARV treatment, L. ceased to adhere to the mandatory drug regimen. Subsequently, clinic staff learned that this was due to the fact that he had been hospitalized for a broken arm caused by a gunshot wound. Therapy was rapidly resumed, and he improved significantly; but after six months of therapy, his nonadherence to the treatment became manifest. His CD4 count was barely improving, and his viral load remained detectable at 3- and 6-month routine checkups. Shortly after 9 months on ARV medications, his clinical status worsened, and he developed pulmonary tuberculosis. He was urged by the staff to attend intensive counseling sessions, which he did. He improved once more for a short while, but "defaulted" again in the taking of his medications and vanished from sight. When he reappeared, his clinical status had deteriorated still further. At this point, the Khayelitsha team painfully decided to withdraw ARV treatment, not only because the clinical signs indicated that it was not benefiting him anymore, but also because they hoped that this would produce a "reality shock" that would forcefully remind him about the importance of "regularity" and "adherence." Their strategy did not work. L. died from disseminated tuberculosis 18 months after he had received his first dose of antiretroviral drugs.

One could say that virtually until the day L. died, the staff did not relinquish their intention of finding a way to maintain him on ARV treatment. In their eyes, his was a "tragic history." His way of life, and his "competing priorities," they felt, grew out of his enormous frustration over his unemployment and subsequent inability to "put bread on the table" and fulfill other traditional obligations of a Xhosa-African man (a predicament that pervades the lives of many male inhabitants of Khayelitsha). Although he tried to cope with his frustration through his HIV/AIDS-focused political activism, he never succeeded in sufficiently "overcoming his demons," as one physician put it, "to achieve regularity in treatment." There is a sense in which the staff's understanding of L.'s social, economic, and cultural situation and his reactions to it made it harder for all of them to decide as they did. In the end, however, it was the doctor in charge of the case who was the most emotionally and ethically disturbed by the outcome. Although he regarded the withdrawal of ARV treatment as clinically justified, he felt a sense of responsibility and failure over the fact that this decision "did not offer any future to a charismatic patient," to whom his physician's fidelity was strong. The chief counselor who was involved in

the case found some consolation, as well as justification, in the fact that according to the criteria of patient adherence, which it was her professional obligation to monitor, the decision to stop treatment was the "right one."

Reluctance to Accept Patients' Refusal to Begin or Continue ARV Treatment

Staff not only find it difficult to refuse ARV treatment; they are also averse to acquiesce in the decision of some patients not to start or not to continue ARV treatment. The following cases illustrate the point.

A., a terminally ill 34-year-old man, with a CD4 count of 9, in Stage 4 of HIV/AIDS, was described in a selection committee meeting as having displayed "repeated adherence problems" in the past. He had failed to show up for clinic appointments, and at one point he had "disappeared" from Khayelitsha to return to the Eastern Cape, his region of origin, for a prolonged period of time. It was reported in the meeting that A. had vocally objected to the fact that family members-particularly his aunt, who was his devoted caretaker—were "forcing" him to seek treatment. The committee engaged in more discussion about this patient than usual, especially because A.'s aunt strongly advocated that he should receive treatment. However, his HIV/AIDS had progressed so far that he was no longer "responding," and able to give his own informed consent for it. Although the physician presenting A.'s case stated that "even if we start him now [on therapy], he is likely to die in a month," the committee decided to immediately begin treating him with ARV drugs and to monitor his case on a weekly basis.

S., a 31-year-old taxi driver was sent to the Khayelitsha HIV/AIDS clinics by the GF Jooste Hospital, the project's referral hospital. He had been diagnosed with criptococcal meningitis and was in Stage 4 of HIV/AIDS. His wife and 5-year-old son were also HIV positive. Because of the clinical stage of his disease, he was rapidly selected as a candidate for ARV medications. However, he refused to start treatment for several months, insisting that he wanted his wife to become pregnant before he began the therapy. Having sexual intercourse with his wife without using a condom contravened the safe sex policy to which patients were expected to adhere. S.'s wife, who was well informed about HIV issues, was started on ARVs. Two months later, she became pregnant. Once this occurred, S. stated that he was now ready for ARV treatment, and his treatment was begun. His wife then underwent an abortion, claiming that ARV drugs had toxic effects on a pregnancy. Subsequently, both she and her husband stopped taking the ARV medications. Their current whereabouts are unknown to the Khayelitsha staff-but were they to appear again, it is not inconceivable that the decision would be made to resume their ARV treatment.

Acceptance of "Queue Jumping"

Staff members are very concerned to avoid acting as a judgmental "tribunal," making life-or-death decisions in the process of trying to ascertain which patients will and which will not benefit from ARV treatment. This is particularly apparent when they are confronted with patients in a very advanced, rapidly evolving stage of HIV/ AIDS who have a high risk of imminent death. When faced with the question, "Who shall live when not all can live?" 7 they are inclined to allow these persons to "jump the queue" of what are usually around 500 patients with CD4 counts of less than 200/ml waiting to begin ARV treatment. They do so with the uncomfortable knowledge that such "fast-tracked" patients will not only delay the treatment of other patientcandidates who may have been waiting longer, but may also contribute to the further deterioration of their immune function because of the extended waiting time.

Selection in the Khayelitsha Project—Not a Unique Experience

Members of the Khayelitsha selection committees have found it difficult to refuse treatment to any patient, independently of the selection criteria. They are also reluctant to accept patients' refusal for treatment, and they fasttrack some patients whose health status has become precarious. These are not unique experiences or singular reactions to them. One of us (R.C. Fox) was reminded of how the Admissions and Policy Committee of the Artificial Kidney Center in Seattle, Washington, USA, felt about their encounters with comparable challenges and the way that they dealt with them.

In the 1960s, this committee was confronted with the task of screening and selecting patients with end-stage disease for chronic intermittent dialysis. At that time, only a limited number of kidney machines and meager financial resources were available for this purpose, making it impossible to accept every patient medically eligible for dialysis. Like the Khayelitsha committees, the Seattle committee developed a set of medical, psychological, and social criteria intended to enable them to make sound and justifiable decisions about which patients were given access to this life-prolonging therapy. But in common with their Khayelitsha counterparts, committee members were disinclined to apply the selection rules strictly. In fact, it was striking how few of the deselection criteria were used. In the manner of the Khayelitsha committees, the Seattle committee focused on choosing, rather than disqualifying, patients whose cases came before them.⁸

One might assume that the moral dilemmas and emotional strains of patient selection for ARV or hemodialysis could be dispelled once the problem of limited resources is resolved. However, this is not necessarily the case, and the follow-up story of dialysis in the United States is instructive in this regard. It became clear that the problem was not restricted to scarce funds and therapies and their allocation.9 Through a law passed by the U.S. Congress in 1972, the treatment of endstage renal disease by dialysis and/or kidney transplantation became available to almost the entire American population.10 But the physicians' unease about "playing God" as gatekeepers of dialysis was not alleviated by universal financial accessibility. In fact, it was replaced by new sources of disquietude. What became acutely problematic now was the lack of means to deselect patients who would not benefit from dialysis, would be subjected to a dubious quality of life, or even (as Belding Scribner, the inventor of chronic intermittent dialysis put it) suffer "a fate worse than death." 11 With access to dialysis freed from financial limitations, it became more emotionally and morally difficult to deny this mode of treatment to anyone with end-stage renal disease. In this regard, selection and deselection issues not only persisted, but were magnified.

Persistent Ethical Questions

Inherent to the thoughtful, self-critical process through which the MSF/Khayelitsha staff has progressively arrived at its evolving system of patient selection are a number of ethical questions with which they continue to grapple.

 In the face of the shortage of staff with which this project, like most programs in countries with a high endemic rate of HIV/AIDS, is faced, how can a proper balance be struck between a public health commitment to offer ARV treatment to as many people as possible (which entails greatly simplifying the follow-up care done mostly by nurses) and medical responsibility to ensure that every patient on ARV treatment receives adequate care, with special attention to the possible development of serious, drug-related side effects and of drug-resistant forms of HIIV/AIDS due to patients' nonadherence to the ARV regimen?

- Under what circumstances, if any, is it justifiable to disrupt an equitable "first come, first served" ARV treatment policy by giving priority to very sick AIDS patients, who may be on the brink of death, letting them jump the queue of less drastically ill patients with better prognoses, whose medical conditions may deteriorate while they await treatment?
- Requiring candidates for ARV treatment to disclose their HIV status to at least one family member, to allow a home visit by a counsellor or nurse in case of perceived family problems, and to attend a support group may improve the potentiality for treatment adherence and contribute to the overall destigmatization of HIV/AIDS. However, do these eligibility criteria violate the obligation of healthcare personnel to maintain confidentiality about patients' medical conditions and to protect them against any coercive divulgence pressures?
- Is it acceptable to suspend the ARV treatment of a patient who is not taking his/her medication regularly in order to avert the

- development of a drug-resistant form of the HIV virus, on the assumption that the patient will subsequently cease this nonadherent behavior and recommence treatment before a fatal outcome occurs? (Note that in the case of Patient L., this strategy did not work, and he died of disseminated tuberculosis before ARV treatment was resumed.)
- Does the fact that ARV treatment is now available more widely, at other sites and in other provinces, legitimate the alteration that the Khayelitsha project has made in its previous requirement that all persons with HIV/AIDS accepted for therapy in its program be permanent residents of that township-substituting for it patients' agreement to remain there for at least 6 months and opening up the possibility of their transfer, after that time, to another treatment center in the geographical area to which they may want to move?
- And is it any longer justifiable for the program to maintain its policy of initiating ARV treatment in pregnant women whose CD4 count is below 200 to prevent the mother-to-child transmission of HIV and then discontinue this life-saving treatment for her after she delivers her baby if she desires to return to the rural interior of the country, where it has been assumed until now that she will not have access to the ARV drugs on a regular basis?

Conclusion

The so-called universal rollout of ARV treatment for all who need it has only begun in South Africa, and the country is far from dealing with or even anticipating what patient selection and

deselection issues achieving that goal may entail. But the process of "scaling up" ARV treatment that has been launched has already made it apparent that the problems of selecting patients for ARV treatment with which the Khayelitsha project has been struggling in the microcosm of its township will not only persist for some time but may even be amplified in certain ways.

Expanding AIDS treatment on a national scale is an intricate public health challenge. A distributive ethics, oriented to benefit the greatest number of persons in all regions, communities, economic, social, and cultural groups in the country will have to prevail over an individual ethic that gives precedence to the well-being of each patient in a one-on-one relationship with healthcare professionals. It is likely to be accompanied by areas of tension between them. The South African government's Operational Plan for Comprehensive Treatment and Care for HIV and AIDS will need to be phased in incrementally, bringing in its wake questions about the order in which treatment centers will be established in the different districts of the country and the priority and provisions assigned to them. The foremost hindrance to the full implementation of this plan is the dearth of physicians and nurses to treat and care for all the persons with HIV/AIDS in the population, rather than insufficient funds or supplies of affordable ARV drugs.¹² What is more, expanding ARV treatment on a society-wide scale will probably require major changes in the entire South African healthcare system, whose current status is described by professor of medicine Solomon R. Benatar in the following way¹³:

Considerable legislation has been passed with a view to achieving greater equity in access to healthcare with a district-based primary health care system. To achieve this, national public health resource allocation is focused on redistribution away from tertiary care towards primary health and community-based care. However, excessively rapid transformation towards these goals has resulted in dysfunctional primary services and attrition of tertiary services in the public sector with greater losses than gains in healthcare in the short term and adverse implications for the future.

Within this already burdened system of healthcare delivery, major issues of how to allocate its personnel, facilities, and energies between the treatment and care of persons with HIV/AIDS and all the other health and medical problems of the country's citizenry will arise and require developmental solutions.

It is the hope of the MSF Khayelitsha program that what they have learned on a local scale from their first-hand experience in dealing with medical and ethical issues of what they call "patient selection" can make a constructive and edifying contribution to this at once urgent and formidable societal process.

Notes

1. Initially, the Khayelitsha program was mainly supported by private funds from different MSF sections, Belgian and Danish Cooperation funds, the Letten Foundation in Norway, and public funds from the Provincial Government of the Western Cape. At present, 80% of its funding comes from the Provincial Government. Building on their experience in Khayelitsha, MSF-South Africa, inaugurated a program to prevent and treat HIV/AIDS in a remote, impoverished rural milieu in the Eastern Cape of South Africa (Lusikisiki). This initiative was started with financial and moral support from the Nelson Mandela Foundation in 2003. Lusikisiki suffers from the poor health infrastructure and scarcity of health staff that is common to rural areas in Africa and that makes the effective implementation of HIV/AIDS ser-

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- vices a daunting challenge. This is particularly so in the face of adult prevalence rates between 30% and 35%. Nevertheless, the program managed to start 500 patients on ARV treatment during its first year of existence.
- 2. Originally, these drugs were mainly imported from a state-controlled Brazilian company. At present, they are chiefly supplied by Indian companies, and most recently, the first-line, three-drug regimen has been offered to public services for US\$15 per month by Aspen Pharmacare of South Africa. Aspen, based in Johannesburg, is the largest drug company in Africa. It has the permission of GlaxcoSmith Kline and Boehringer-Ingelheim to produce generic versions of AIDS drugs with valid patents for the South African market.
- In 2004, MSF increased its funding once more, making it possible to cover the costs of ARV treatment for 600 persons.
- 4. The implementation of this program has been slow. No more than 65,000 persons of the 500,000+ individuals who need antiretroviral therapy to stay alive are currently receiving it.
- The program that MSF established in Lusikisiki, a very poor and isolated area of the Eastern Cape, has more difficulties in recruiting physicians and nurses than Khayelitsha.
- 6. In an earlier phase of the Khayelitsha project, when funding and access to ARV drugs were scarcer, a home visit to every prospective recipient of treatment was required. At present, this only takes place if counselors feel that they do not have enough information about a patient's family or residence.
- 7. Childress JF. Who shall live when not all can live? *Soundings* 1970;43(winter):339–55.

- 8. Fox RC, Swazey JP. The Courage to Fail: A Social View of Organ Transplants and Dialysis. Chicago: University of Chicago Press; 1974, 1978 (second, revised edition), and New Brunswick and London: Transaction Books; 2002 (republished with a new Introduction). See especially, "Patient Selection and the Right to Die: Problems Facing Seattle's Kidney Center," pp. 226–65.
- For a detailed account of some of the unanticipated as well as anticipated consequences of the "democratization of dialysis," see note 8, Fox Swazey 1978:345–75.
- 10. With the passage of Public Law 92-603 on October 30, 1972, Medicare insurance coverage for dialysis and transplantation was extended from those over 65 years of age covered by the original 1965 Medicare law to more than 90% of the United States population.
- 11. See note 8, B. Scribner, personal communication quoted in Fox, Swazey 1978:373.
- 12. This problem exists throughout the continent of Africa. In a report released on November 26, 2004, the Joint Learning Institute, a research group of some 100 scholars and experts financed by the Rockefeller Foundation and the Bill and Melinda Gates Foundation among others, stated that Africa needs a million more health workers to deal with the HIV/AIDS pandemic. In this connection, it exhorts rich countries to stem the "fatal flows" of nurses and doctors from poor African countries to Europe and North America. (See Dugger CW. Africa needs a million more health care workers, report says. New York Times 2004, Nov 26:A27.)
- 13. Benatar S. The lost potential of our health system. *Cape Times* 2005, Jan 14.