Since 1990, parallel to the period of transition to a democratic society, the AIDS epidemic in South Africa has increased dramatically. The level of HIV infection in the adult population (ages 15–49) rose from 1 percent in 1990 to more than 20 percent in 2000. However, this figure conceals a disparity in the distribution of the disease. The townships are affected far more than the largely white suburbs, while in the townships themselves the highest levels are found in the so-called squatter camps (Shisana and Simbayi 2002). The combination of pandemic and democracy has wrought changes specific to sufferers living on the periphery of Johannesburg. People obtained their freedom and fell sick at the same time. The newly acquired sovereignty has enabled individuals to explore previously unavailable urban spaces, to develop innovative forms of political mobilization, and to access, in new ways, health services that had once
been forbidden to them. The practices of these suffering bodies are the focus of this essay.

Generally the body that is inscribed in most scholarly work on the city is the healthy body. Theorists of modernity regard the city as the place par excellence for the realization of the individual. If the individual suffers, it is usually from isolation and anonymity (Simmel 1971). Otherwise, the individual is autonomous and free from disease. It is with reference to this presupposed healthy body that typologies (Hannerz 1980) and concepts such as mobility, trickery, and poaching (Certeau 1990), strolling (Baudelaire 1968), and wandering (Benjamin 2002) have been developed. These concepts have also subsequently been used to give meaning to a whole set of daily urban practices (Gibbal et al. 1981; Bourgois 1995; Villers, Jewsiewicki, and Monnier 2002). In these works, the body is considered as a medium for or object of various practices, which are in turn the subject of analysis. Even if such practices lead to a deterioration of the body (Bourgois 1995), the body *sui generis* is not present in their definition as such.

In what follows, I take the suffering body as the starting point for a discussion of the city. In making use of the life stories and itineraries of AIDS sufferers living on the periphery of Johannesburg, I redraw the map of the city outlined by the bodies of those who are poor, hunted, suffering, and in search of care. I show how, far from being immobile, the sick body moves and travels. In doing so, it shuttles constantly between private and public spaces, unveiling the city through its movements. I show how the body afflicted with AIDS itself constitutes an archetypal figure in the city of Johannesburg and how, in its search for care and for sanctuary, it acts as a place of mediation and meeting between the public and the private, the official and the unofficial, the here and the elsewhere.

The majority of the sick have no fixed income. Some receive a disability grant of R700 a month on the basis of their HIV status, but for many, mobility and trickery are the means of survival (Certeau 1990). Underlying their struggle is a quest for social and therapeutic support and, for some, a quest for social recognition through militant involvement in HIV/AIDS associations. The Johannesburg itineraries described here do not cover the entire experience of those living with HIV/AIDS, but they do allow an understanding of certain fragments of that experience and urban reality. Johannesburg, in this reality, appears as a series of dots, with cardinal points in certain public places (health centers, administrative buildings) and other sites where sick people are hiding or where they are known only as nearly dead bodies (houses where the sick find refuge, unofficial places of care,
hospices for the dying, and finally, the cemetery). There are also other destinations, places of transit and stopover that together weave an urban fabric, the fibers of which are familiar only to those who are HIV positive.

Along these journeys, Johannesburg also appears in its ambivalence; that is, the city appears as an expression or sign of the harshness of the world but also, occasionally, as one of compassion. Just as it authorizes the exploitation of the sick, so it opens up a myriad of possibilities in terms of care and mobilization. The itineraries of these suffering bodies in the city thus draw a map of the management and the geography of AIDS in Johannesburg.\(^3\) An exploration of these journeys is not limited to that of care. It brings to light the fact that these bodies and selves belong to the urban reality and, more broadly, to the field of national issues as well as to the globalized world. They are integrated, for instance, into the exchange of pharmaceutical products on a global scale, an integration that exposes them to the violence of the market and to exploitation. Other circuits are also explored that allow the suffering bodies tracked here to become people of the *polis*. In this capacity, they form part of the emergence of a civil society.

**Places of Suffering and Places of Mercy**

For those who do not work or whose families have no income, the capacity to travel in the city often depends on the receipt of the disability grant. This is the case for Dalene, a 28-year-old woman who lives in Alexandra. Formerly a part-time cashier in a supermarket, she was the only person providing for her mother and sisters, with whom she lives. Her father left them long ago. Now seriously ill, her monthly disability grant of R700 is the sole source of household income. Receiving it at the end of each month revives Dalene's vague desires to travel within the city; it also means she can afford a taxi and hospital consultation.

\(^3\) The Department of Health in the municipality of Johannesburg provides the following statistics on its Web site (www.joburg.org.za/services/health1.stm#hiv):

At Johannesburg Hospital about 30% of pregnant mothers tested are HIV-positive. Of children tested on admission to the paediatric wards, 40% are HIV-positive, and 75% of paediatric deaths—mostly children under the age of two—are AIDS related. The overall infection rate for Johannesburg of 26% is greater than the average for Gauteng, which stands at 23.9%. The City of Johannesburg is home to a population of 2,883,226 people in some 791,367 households. The population is projected to rise to 2,986,228 in mid-2005 and 3,103,182 in mid-2010. The average rate of population growth for the City of Johannesburg between 2000 and 2010 is projected to be 0.9% per annum. The HIV/AIDS epidemic is largely responsible for this low rate of growth, along with a low fertility rate in Johannesburg.
When Dalene’s health was good, she used to enjoy visiting the shopping malls in Sandton, the nearby wealthy suburb, but today such excursions are barely possible. In addition to being generally very frail, she is suffering from a suppurating abscess on her hand, which gives off a foul-smelling odor. The arrival of visitors with transport makes the family more amenable to Dalene’s wishes. We agree to take her to Edenvale Hospital, a few kilometers south of Alexandra.

Logbook, Alexandra, June 5, 2002

We arrived and waited for her to get dressed. She was wearing a beige jacket that had clearly just been dry-cleaned (the label was still attached) and a pleated lilac skirt. She was also wearing very nice evening shoes. These clothes must have been one of her best outfits. She clearly wanted to make a good impression. Her sister and mother helped her to get ready. Her mother combed her hair and cleaned her hand (the reason for going to Edenvale Hospital). Her sister got her papers together and put them in a multicolored woven straw bag. Despite these devices, Dalene’s generally feeble condition, the bad smell that surrounded her, and her thinning hair meant that all these efforts were rather pointless. When she went out into the street to get into the Beetle, the neighbors gathered round as if at a show, silent and curious. They were as intrigued by our presence as by Dalene’s outing.

Dalene had already seen several doctors about her hand, first at the university clinic in Alexandra (First Avenue), then in Parktown, at the Johannesburg General Hospital. But the treatment she had been given (betadine and antibiotics) seemed to have had no effect. Edenvale was a last try. It was there that she had given birth and discovered her HIV-positive status, but she had never been back.

Normally, Dalene would have had to take a minibus taxi to get to Edenvale Hospital. The journey costs R9 round-trip. She would have walked up the length of Hofmeyr Road to reach the western edge of the township. A business zone called Pan Africa is situated there, the departure point for the township taxis at the north end of First Avenue. She would have waited until a minibus taxi going to Edenvale Hospital filled up with the requisite twelve people before leaving. She had made this journey several times before, but now it would have been impossible, given her ill health. We leave the congested streets of Alexandra and drive into Canning Road, after crossing London Road, which marks the southern boundary of the township and which is lined with factories. Some are disused and inhabited by squatters. One factory still in operation manufactures the condiment *achar*, filling the road with the smell of oil and spices. Furthest from Alexandra, on
Vasco de Gamma Road, other factories have been turned into churches, such as the Rhema Church. The same phenomenon can be seen in the center of the township, where the Universal Church has been established for some time.

Once over the “industrial quarantine line,” a vestige of apartheid politics dedimating the place of work as a privileged meeting place between blacks and whites, the road winds down through a small valley passing through the suburbs of Bramley View Ext, Lombardy West, Corlett Gardens, and Rembranndt Park. Before the demise of apartheid, these suburbs housed middle-class white families. After apartheid, some of these families sold their homes and gave way to an emerging black middle class. Canning Road eventually becomes Wordsworth Road and then joins Modderfontein Road in Edenvale.

The whole journey follows the Jukskei River. This narrow river traverses the township and links it, like Ariadne’s thread, to Edenvale Hospital, whose grounds it runs through. In Alexandra, there are still shacks in some places along the banks of the Jukskei River. In Edenvale, the river is bordered by open fields, where children from the neighboring suburbs used to play before the end of apartheid (today the area seems less secure and these fields remain empty). Edenvale Hospital is situated on a leafy green hill, accessed by a road that links Modderfontein to the center of the city. At the entrance to the hospital, street traders sell sweets, cigarettes, and other goods to people waiting for minibus taxis to take them back to the township. During the apartheid period, this hospital was a public hospital reserved for whites. The inhabitants of Alexandra had to go to Baragwanath in Soweto. Today Edenvale Hospital is inundated with patients referred from various Alexandra clinics.

From clinics to hospitals, Dalene tries to hedge her options by rewriting her medical history and hiding her HIV-positive status, which she feels, often justifiably, to be an obstacle to good care from the health services. Following this logic, although she is doomed to failure because of her physical appearance, Dalene opens a new file when she arrives at the hospital rather than handing in her old one. The files of patients known to be HIV positive are marked with signs or abbreviations recognizable to health professionals, which alert them to the patients’ status.

The coding of HIV-positive patients is linked to the politics of hospital management. Faced with a major shortage of hospital beds, the doctors often choose not to admit HIV-positive patients at an advanced stage of AIDS, because their chances of recovery are limited, while they would admit someone with the same symptoms who is HIV negative. By not admitting an HIV-positive patient, the doctor can keep the bed for an HIV-negative patient or someone at a less ad-
advanced stage of the disease. Days of hospitalization may be saved given that the results of treating HIV-positive patients are somewhat unpredictable.

By changing her file, Dalene is changing her status. After a two-hour wait for an outpatient consultation, she leaves the hospital, fed up with queuing and with little confidence in the outcome of the consultation. In any case the nurse at reception had remarked, even before greeting her, “Here, we don’t deal with that”—gesturing toward Dalene’s purulent hand. Later, her condition deteriorating, Dalene’s family has her admitted to Mother Teresa House, a hospice in Yeoville. She stays there for a few weeks before dying.

When families can no longer take care of the sick, or when those who are ill live alone and home visits by volunteers are not effective, some make a final journey to one of the hospices near the center of town, for example Mother Teresa House or the Rhema Church Service Foundation in Hillbrow. Once again, the trip leading to death passes through the city or, more accurately, through the places of pity and mercy that reinscribe the instability of life in the city at the center of the subject’s consciousness, an instability that we can see as part of the nature of modernity itself. While elsewhere the city seeks to show itself in the shape of the bar, the café, the restaurant, the shop, or the motorway, here it appears as a final attempt to render the last moments of life humane.

Protected behind high walls, Mother Teresa House is situated on a quiet street and surrounded by small houses. Apart from the name “Mother Teresa House” inscribed in blue letters on the front of the building, there is nothing to hint at the drama that takes place behind its walls. The hospice is unobtrusive; only the arrival of emaciated bodies betrays its anonymity. It is a two-story building: On the ground floor there are a chapel, a waiting room, and a men’s ward. Upstairs there are two women’s wards. It is a clean and tranquil place, where patients are given a courteous welcome by a sister of the order of the Missionaries of Charity, dressed in a sari and smiling reassuringly.

Patients must give the hospice advance notice of their arrival to avoid being sent away for lack of space. Once patients have been admitted, they receive care and food. This welcome contrasts sharply with the long wait required to be admitted to public hospitals and, generally, for any consultation in the public health sector. Admittedly, the health services have to deal with a large number of patients and small, overworked staffs, who are unable to attend to patients quickly. In practice, in a primary health care clinic—the first stage in the system—patients normally wait about two hours before being seen by a nurse who, in less than two minutes, sends them to a colleague dealing with the particular problem presented. The patient then finds him- or herself in another queue and is
finally examined by a nurse for an average of five to ten minutes. Sometimes the patient will be redirected to a health center further up the ladder, either to be seen by a doctor or to be hospitalized. For the suffering body, the rhythm and the temporalities of the city are often characterized by waiting. There is no movement. Only knowing how to wait.

The outwardly gentle appearance of the hospice should not conceal the seriousness of admission to Mother Teresa House: one comes here to die. The patients have no misconceptions about this; nor do those who accompany patients who have no family support: they sign a discharge form authorizing the organization of a pauper’s funeral. These funerals are provided by the Department of Social Services. A dismal cycle then begins in which the patients impotently witness the regular departures of their neighbors on the ward, awaiting their own turns. Here the city comes to a standstill. Here, too, the journeys of the sick come to an end. What leaves the hospice is no longer a body, but the remains, a corpse. The body as such is henceforth confined to bed, all but immobile. The city, for its part, grows dark—and then disappears. And so vanishes the city’s boundaries as much as the limits of the body and life of the sick person.

The Networks of the Sick

Visits to clinics, then to hospitals, thus form a “first circle” of exploration, before the hospice. Turning to the hospital offers an opportunity for leaving the area where care is organized around the clinic. In Alexandra, the Health Centre and University Clinic (a clinic that has the status of a nongovernmental organization [NGO] and is better known as the First Avenue Clinic) is found at the western edge of the township. In contrast to public clinics, which offer primary health care services, the First Avenue Clinic has doctors, an emergency service, and a laboratory. Recently renovated, it offers its patients a safe and peaceful haven in addition to treatment. Even the architectural structure of the clinic (several houses linked by corridors around a grassed courtyard) breaks with the unimaginative model of the public clinics (usually rectangular redbrick buildings with consulting rooms distributed along a central corridor). The patients and their families often sit in this courtyard, turning it into a convivial waiting room. During the states of emergency in the 1980s, the clinic was reputed to have protected United Democratic Front (UDF) militants from the police. It is said that nurses used to “lose” the files of patients wounded by bullets, because the police would try to identify participants in the clashes by examining the consultation records.

A symbol of Alexandra’s involvement in the struggle against apartheid, the
The clinic maintained its involvement with the people of the township during the violence that rocked Alexandra before the 1994 elections. In order to reach patients for whom the area around the clinic had become a no-go area, mobile units were set up that traveled around the suburbs. The older employees have nostalgic memories of that period of the struggle when the clinic was united around a shared sense of service to the community of Alexandra. Today the clinic faces a huge influx of patients. From seven in the morning, the benches along the walls of the corridors are filled with people waiting for treatment. Both patients and nurses complain that medicines are often lacking. Nevertheless, for the people of Alexandra who are HIV positive, the First Avenue Clinic remains the closest and most effective place of treatment. It is often there that they are tested for the first time and learn of their HIV-positive status.

However, it does not take long for the clinic to reach its limits, forcing patients to search elsewhere for treatment. Medicines that are normally distributed free of charge (immunity boosters, vitamins) are rarely available in the pharmacy. Other places, such as the Johannesburg General Hospital (JGH), seem to have adapted better to the demand. The JGH in particular has a dedicated clinic for AIDS sufferers. The hospital has greater technological resources and often a wider range of medical specialists. Yet it still features the same structural problems as the clinics. At Baragwanath Hospital in Soweto, the admissions procedure takes an exceptionally long time, and patients must be present for the entire process even if they are quite weak.

The admissions area at Baragwanath is filled with patients lying on stretchers, files in their hands or, if they cannot hold them, slipped under the mattress or under a leg. This admissions process—which limits the possibility of fraud by preventing the admission of virtual patients—creates, in effect, a glut of bodies, more or less living. At Edenvale Hospital the situation is somewhat different as the hospital still benefits from its former status as a hospital for whites. It is situated on a hill, and the large windows in the reception hall provide a panoramic view of Johannesburg. The admissions procedure is no less cumbersome than at Baragwanath, but the hospital has the advantage of a more modern infrastructure and a more humane admission process. For example, the patients are invited to sit in a booth so they can complete the admitting forms in privacy.

AIDS thus quickly demands ever-increasing circles of exploration, obliging sufferers little by little to crisscross the city. The options provided for HIV-positive patients by the public services (clinics, hospitals, social assistance), the NGOs and the churches (support groups for patients), and the various therapy or education options are spread out across the metropolitan area. The patients cir-
culate among these different places depending on their means of transport and the quality of the service offered. This applies, for example, to patients wishing to obtain a medical certificate on the grounds of physical incapacity, a prerequisite for receipt of disability grant. The rules state that a medical certificate can be issued only if the individual concerned is physically unable to work. Some doctors consider an individual with a CD4 T-cell count of two hundred or lower to be eligible for the grant. Others are willing to sign a medical certificate as soon as the individual is HIV positive.

These movements around the city often begin with support groups for people living with HIV/AIDS. The activities of these groups, which vary according to their coordinators and institutional affiliations, include the exchange of information, advice, and experiences of patients, organizing home care, and delivering food parcels. Generally, the advice given to the members of support groups focuses on the idea of a “healthy lifestyle.” The literature distributed at the clinics by the Department of Health advises patients to “take care of your health (eat properly, do physical exercise, get enough rest), have a positive outlook on life (set personal objectives, believe in yourself, see the positive side of things, be aware of your strengths and weaknesses), try to get the support of those around you (family and church), practice safer sex”: all designed to ensure a “healthy lifestyle.” The coordinators generally sum up the expression “healthy lifestyle” by condemning alcohol consumption and tobacco use and encouraging the use of condoms.

To address participants’ nutritional problems, meals are sometimes provided at the meetings, or food parcels are delivered. The groups vary considerably according to their institutional affiliation. Some are run by local or international NGOs, others by churches. They may also be organized in the context of research programs on HIV/AIDS. The support groups’ knowledge of the pandemic and related issues, as well as their financial resources, depends in some measure on their institutional support. Some groups develop income-generating projects (e.g., handicraft workshops, vegetable gardens). “Memory boxes” are another type of project. These allow sufferers to prepare for their demise by leaving traces of themselves for their families in the form of texts or photographs. The groups also

4. CD4 T cells are known as “helper” cells. They track down germs in the body and destroy them. The HIV invades the cells, reproduces itself within them, and eventually kills them. A CD4 count indicates the different stages of the HIV infection. A healthy body has a CD4 count of 1,000–1,500 cells per cubic millimeter of blood. A CD4 count below 200 indicates that a person has reached the fourth stage of the illness. This person would be said to have AIDS (i.e., he or she is no longer simply HIV positive). See Evian 2000.
serve as a forum for discussing common dilemmas, such as disclosing one’s HIV status to family and social circles or the possibility of having a child.

HIV-positive individuals are referred to support groups most often by the clinics, but word-of-mouth also plays a role. A young HIV-positive woman, who had recently joined such a group, said, “When I was phoning Elsy saw me. She called me. She said she was going to take me there and there, and she started telling me about the support group. If it was not because of her, I would have known nothing.” The arrival of a new member begins with an interview with the group coordinator. This interview takes the form of a confession during which the newcomer relates his or her personal history. The newcomer is then introduced to the other members who in turn introduce themselves briefly by giving the date on which they discovered their HIV status: “HIV positive since 1999, for three years.” The newcomer introduces him- or herself last. Each person’s story is revealed little by little or not at all, in full or in part, depending on the relationships that develop within the group. The initial sharing of the date of infection gives a common base that provides a driving force for these groups. It does not, however, imply any unconditional sharing of experiences or suffering. The coordinator normally remains the primary facilitator among the members of support groups. He or she often enjoys a privileged relationship with the social or health services and as a result may be able to intervene positively if necessary—providing access to grants, assistance in cases of domestic violence, and consultation on specific health problems.

Attending a support group sometimes means journeys over long distances, not because the groups are few but because patients tend to look for confidentiality. Porshia lives in a shack in Dobsonville. She found out that she was HIV positive after she was raped during a visit to her family’s home in the Transkei. She attends a support group in Diepkloof (about twelve kilometers from Dobsonville), which allows her to conceal her HIV status and her rape from her neighbors. Similarly, individuals living in Orlando East, rather than attend the support group in their neighborhood, avoid unwanted encounters by attending the Diepkloof clinic’s group in the adjacent suburb. In effect, weekly visits to a neighborhood clinic (groups generally meet once a week) could lead neighbors to gossip about one’s HIV status and raise suspicions within one’s own family, who are often unaware of the situation. In some cases, the disclosure of HIV-positive status leads to discrimination by the family: family members may stop sharing food with the sufferer, or he or she may be asked to stay alone in a backyard shack instead of staying inside the house. The family may also fear being seen as a “host” to the illness in the neighborhood. Of course these reactions are not sys-
The Suffering Body
of the City

463

tematic and differ from one place to another, from one family to another. Never-
theless, they often justify people’s need to hide their HIV-positive status.

Elisabeth lives in a shack in Diepkloof and does attend the support group at
her local clinic. To explain her frequent visits to the health center, she says that
she is being treated for tuberculosis. A young man living in Yeoville attends a
clinic and support group in Alexandra. In his case, the desire for confidentiality
goes together with a search for quality treatment. The clinic he attends in Alexan-
dra seems to him to offer a better service than those that are closer to where he
lives. Domestic workers in the northern suburbs of Johannesburg, not far from
Alexandra, also provide the township clinics with their quota of patients in search
of free treatment. The city drawn by the support group is thus made up of juxta-
positions and enclosures. It is made of fragments of anonymity. The individual
wanders through it wearing, of necessity, a mask. This is a dispersed metropolis,
where place has sense only in relation to a duplicate that simultaneously hides
and erases it.

Epidemic, Sales, and Profits

As centers of information exchange, the support groups also act as places of
recruitment for therapeutic trials or for commercial activities, introducing suffer-
ers to more and more complex networks that effectively turn the city into a veri-
table labyrinth. Individuals’ participation in these different networks is inscribed
within the framework of a search for treatment. Confronted by the absence of a
definitive therapeutic response to their disease, HIV-positive individuals who can-
not purchase antiretroviral drugs through private doctors seize any opportunity
that presents itself and thus serve up their bodies to therapeutic trials.

Some tests are legal and are supervised by competent authorities. This is true
of therapeutic trials conducted at Baragwanath Hospital in the PHRU (Perinatal
HIV Research Unit). Here, all tests are subject to a validation request from the
ethics committee of the University of the Witwatersrand. When tests concerning
new medicines are involved, they are submitted to the MCC (Medicines Control
Council) and to the Gauteng Province Protocol Review Committee. In some
cases, the Faculty of Health Sciences Institutional Review Board is also con-
sulted.

Other tests are conducted secretly and carry no guarantee for the volunteers.

5. The support groups, in fact, are one of the few sites where churches, pharmaceutical companies,
and social science and medical researchers come into contact with sufferers.
A young HIV-positive man belonging to an Alexandra support group was re-
cruited in the street to take part in clandestine trials in Yeoville. On this particu-
lar day, his only mark of identification was a T-shirt on which was written “HIV Positive.” A white man approached him and explained that he was looking for volunteers on behalf of a friend. These volunteers were needed to take part in AIDS therapeutic trials. He invited him to come along and bring with him any HIV-positive friends. Five members of the young man’s support group turned up at the selected venue. There they found other patients who had been sent by a nurse at the Johannesburg General Hospital in Parktown. For three months, they received ultrasound therapy once a week in a flat in Orange Grove, an opulent northern suburb of Johannesburg. The contract the participants signed required them keep the treatment secret because, they were told, the government refused to take care of HIV/AIDS sufferers and would probably try to eliminate anyone who was able to find medication.6 During the trials, these guinea pigs were given nutritional supplements and sent to a private Parktown clinic to evaluate the effect of the treatment on their CD4 counts and viral loads. Their transport costs were covered. Later, they were taken to a public hospital in Pretoria for control tests because the costs were lower there. The trials ended without any results being communicated to the volunteers. The participants in these trials revealed their experience to the rest of the support group only later, when the feeling of having been exploited got the better of their hope for a cure. Moving in an economy where limited treatment is available favors the concealment and the compartmentalization of networks.

Within the framework of these secret therapeutic trials, sufferers are displaced from home to clinic and obliged to make trips out of the townships only to serve as guinea pigs. When these journeys are finished, sufferers often have nothing more to show than a worthless contract and a few laboratory bills. One of the volunteers claimed that an opposition party seeking to oppose the African National Congress (ANC) on the issue of AIDS had financed the trials in which he had participated. There was no proof of this, but it may well be that the epidemic has become a factor in the party political struggle. The more Thabo Mbeki’s denial

6. The idea of a government conspiracy against poor HIV-positive people is shared by many living on the fringe of the townships. The government’s nonintervention policy is seen as an attempt to reduce the number of poor people in South Africa. This idea developed in the midst of a controversy in South Africa over President Thabo Mbeki’s denial of a link between HIV and AIDS. The controversy came to an end in November 2003 when the government announced a comprehensive plan to distribute antiretrovirals. For an analysis of the controversy, see Fassin 2002, 2003; Fassin and Schneider 2003.
was publicized, the more the issue of AIDS became a key aspect of the opposition's criticism of the government. If the debate concerned the question of the delivery of antiretroviral drugs, it was also deeply inscribed in the history of race relations in South Africa and more generally in the context of North-South relations (Posel 2003). Experiences of such therapeutic trials in the opulent northern suburbs leave a rather bitter taste in the mouth.

Similar things happen in the townships. The same impunity protects those who, on the pretext of looking for an African cure for AIDS, exploit the bodies of the sick and thereby earn money, charging patients up to R1,500 to participate in these so-called trials. In these networks, business and disease turn out to be good bedfellows. Here the logics of individual care at a local level intersect with the logics of profit, politics, and ideology at the national level. In political projects and ideological debates, those living with HIV/AIDS seem to be little more than raw material to be exploited. The intervention of President Thabo Mbeki and the then minister of health Nkosazana Zuma in the Virodene trials of 1998 is just one example of the collusion between politics and the search for treatment. These debates are also ideological because the legitimacy of ethically dubious trials is based on the Africanness of the research carried out. In the name of a search for an African response to the pandemic, some doctors are authorizing the establishment of therapeutic trials without supervision from the MCC and without backing from an ethics committee.

In fact, alongside networks of therapeutic trials—whether official (such as those at Baragwanath Hospital) or unofficial (such as the ones in the townships)—commercial networks are being established from within support groups. One such network is the South African company Pharma Natura, which has specialized in the sale of so-called natural pharmaceutical products for the last forty years. Under the name of one of its divisions, Optilife, it has established a medicosocial orientation center in Wynberg, an industrial area situated near Alexandra township. This center recruits patients from the nearby Alexandra support groups and provides a holistic treatment for the sick. There they can consult a university doctor specializing in AIDS, who points them toward appropriate hospital services, while a social worker gives advice on accessing social assistance. In the waiting room, the patients find a wide range of pamphlets on AIDS, as well
as brochures advertising a variety of natural products manufactured by the company.

These products range from vitamins and nutritional supplements to products for diseases of the skin. The company’s leading products, inspired by anthroposophical medicine, are the Sutherlandia Formula and the VMA Formula. The first is a cocktail of plants (Sutherlandia frutescens and olive leaves), vitamin E, and selenium, while the second is a nutritional supplement. The description of the Sutherlandia Formula draws on idioms of scientific discourse as much as of indigenous knowledge. Vitamin E and selenium are described as “antioxidants” and “immune boosters.” Without ever explicitly mentioning AIDS, the vocabulary used belongs to the register of the epidemic. Along with the scientific term Sutherlandia frutescens, the common South African term is also given—the Afrikaans name Kankerbos (cancer bush). According to the Sutherlandia Formula leaflet, the plant “is regarded traditionally as a medicinal plant in Southern Africa and has enjoyed a long history of use in southern Africa.” Optilife advises users to complement this cocktail of vitamins (two tablets morning and evening, at a cost of R50.50 for a box of 120) with the VMA Formula nutritional supplement (two capsules, one to three times a day, R45.60 for 60 capsules). The terms HIV and AIDS do not appear in the leaflet that describes the supplement, but the disease appears beneath the surface. The nutritional supplement is aimed at those who suffer from “skin rashes, constipation or diarrhoea, weight loss, infections, night sweats”—and other characteristic symptoms of AIDS. Optilife’s business strategy is to not mention AIDS directly so that the stigma attached to the disease does not chase away potential clients. One should be able to purchase these products without signaling one’s HIV-positive status to family and friends.

The initial consultations were offered in the support groups free of charge. Optilife also invested in the refurbishment of the clinic and paid the salaries of the doctor and social worker. Because of low sales, a charge of R30 was introduced for each consultation. However, after a year, in February 2003, the clinic closed down, although there is a network of agents still operating in the city. Each agent receives, after a short period of training, a medication kit worth R150, which he or she is meant to restock as the contents are sold. The more products the agent sells, the greater the profit margin on each product. While Optilife uses a variety of ways to reach its clientele (getting patients to come to them, estab-
lishing agent networks, and contacting the medical services of large companies), others focus primarily on recruiting an army of small-scale traders who travel across the city, visiting HIV/AIDS support groups in various treatment centers. City of trade and city of disease, the informal and the formal, the visible and the hidden—all are intertwined, each embedded in the other.

The dialectic between indigenous knowledge and biomedicine is more marked and the reference to AIDS more explicit in advertisements for the following products than for Optilife. One such product is a drink called Aloe Vera Gel, which is manufactured from the aloe vera plant and said to boost the immune system. Aloe Vera Gel is distributed in South Africa by Pro Peaks on behalf of Forever Living Products, the world leader in aloe-based products. Forever Living Products has had a presence in South Africa since 1995, via local distributors; in 2001, worldwide sales reached $1.3 billion. On its Web site, the company states that its product has been used for centuries: “Aloe vera’s skin smoothing emollients and healing capabilities have been known for centuries. The earliest reference to aloe vera was discovered with an Egyptian mummy from 1550 BC. Alexander the Great used aloe vera to restore the health of his troops. Cleopatra relied on it to help preserve her legendary beauty.”

Aloe Vera Gel is recommended to support groups by retailers affiliated with Pro Peaks. The retailers report that aloe vera has been used for many years in black communities in South Africa. This discourse echoes the current South African debate around the recourse to local “traditional” knowledge in response to the AIDS epidemic. Although it has a local legitimacy, Aloe Vera Gel remains a global product. The company that manufactures it is based in Tempe, Arizona, in the United States. The one-liter bottle costs $16.95 (R125) on the U.S. Web site of Forever Living Products, while it costs R206.85 on the South African distributor’s Web site. The bottle is sold in the townships for between R250 and R300 ($36–$43). Staff in clinics who are responsible for pre- and postcounseling (individual interviews with patients before and after taking an AIDS test) are targeted by a number of retailers selling this kind of product. They are encouraged to direct those who are infected to the retailers, either by telling patients where to find them or by giving out a cell phone number. Once a specific number of patients has been referred, the counselor receives the total profit of one sale from the retailer.

12. Pro Peaks is directed by a couple of South African white doctors who decided to distribute Forever Living products after having tried them themselves; see www.propeaks.co.za/about.html.
This type of network marketing, a function of overlapping roles and common interests, also exists outside of places of treatment. For example, a civil servant responsible for processing applications for a disability grant (accessible to HIV-positive patients) might take advantage of this position to introduce sufferers to a trade network extending throughout the city. One such network was established by a company called Nature’s Health Products based in Rietfontein, a town on the west side of Johannesburg. It extends across all the large cities of southern Africa. Nature’s Health Products has a branch in Florida—a suburb southwest of the city center—and another in Soweto. It markets numerous products that are supposedly effective against AIDS. The heterogeneous names of these “anti-AIDS” products demonstrate the cosmopolitan nature of their market. For example there are products called Amandla (a Zulu word meaning “power”), African Potatoes/Inkomfe, Aloe Vera, Viraforce, Powerlife, and Miracle Muti (muti is a generic term for medication in traditional African medicine). The Nature’s Health Web site indicates the multiple ways that the company ensures the value of its products:

All of Nature’s Health’s products have undergone safety studies and we have scientific proof that they work. They are all manufactured according to international standards and all the regulations as laid down by the South African Medicines Control Council. Nature’s Health’s products are widely recommended by both medical and traditional doctors as well as hospitals and Aids clinics. Currently Miracle Muti is being given on a regular monthly basis to Aids patients at an Aids clinic. Research is being conducted on an ongoing basis to develop new products and to improve existing ones. Our range of products increases every month. As a network marketing company we are actively recruiting new distributors all the time so that we will be able to service our clients and introduce more people to Miracle Muti.14

There is an underlying tension here between a Western reference (“international standards”), a scientific reference with universal value (the South African Medicines Control Council, “medical doctors”), and a secular African knowledge (“traditional doctors”). These three elements form the cornerstone of the sales techniques used by this company. They are also at the center of the debate on the methods of treating AIDS in South Africa as well as at the center of the dynamic of networks explored by those living with HIV/AIDS in the city. When the civil servant in the social services sees an HIV-positive individual, the civil servant

distributes a copy of a promotional article extolling the merits of Miracle Muti. The tension manifested on the company’s Web site can be found here too. In addition, this product is presented as an alternative to antiretrovirals, because it treats just about everything and is, moreover, nontoxic and has no side effects, at least according to the promoters: “MIRACLE MUTI now includes AMANDLA, a powerful combination of five of Africa’s most potent herbs, which in scientific tests has proved to be very successful in the fight against HIV/AIDS because it is anti-viral, anti-fungal, anti-bacterial, antiseptic, and anti-inflammatory. Amandla is completely safe, non-toxic and without any side effects.” The article encourages the reader to contact the distributor of the medication and includes the phone number.

Nature’s Health locates potential customers in part through the intricate networks of HIV/AIDS patients, as in the case of Ntombi, who lives in Alexandra. She discovered her HIV-positive status a year ago, when she was pregnant. She has tried all kinds of treatments ranging from immune boosters to healing rituals in the Zionist Christian Church to muti purchased here and there. After joining a support group, she was directed to the nearest welfare office to apply for a disability grant. When she read the article referred to above, she made the telephone call. A white woman replied, which surprised Ntombi since she thought she was dealing with a black African muti. Indeed, some companies exploit the contemporary mood for an African herbal cure for AIDS, and in so doing they transgress the racialized assumptions about so-called indigenous cures. Ntombi described her symptoms (weight loss, diarrhea), and the woman assured her that if she took this Miracle Muti she would feel much better. She also explained to Ntombi that the bottle would cost R295 on the day of the conversation but the price would increase by R100 the following week. She asked her to take a minibus taxi to Florida and to phone again once she arrived so that she could be fetched from the taxi rank.15 This city of suffering bodies is thus also a stream of stories and narratives accumulated by individuals, as well as of disappointments experienced along the myriad paths they traverse in search of treatment.

Ntombi’s physical weakness and the fact that she does not have access to diverse social networks make her vulnerable to all kinds of exploitation. On one occasion, she visited her area clinic where a nurse informed her that there was a shortage of medicine. The nurse advised Ntombi to buy some Bio Sil (an immune system booster sold both in pharmacies and door to door) and directed her to a nurse at Baragwanath Hospital in Soweto who sells herbs and medicines that

15. Taxi rank is the South African term for a taxi stand.
counteract AIDS. There are countless such examples of people unable to receive care from public health services and referred to the private sector for *muti* or drugs.

The vitamin cocktail High Impact Vitamins has been on the market for several months. In the product description, it is called HI-Vite, which leaves little doubt as to the HIV status of the target market. The leaflet in circulation has three photos. The first shows “cold sores and fever blisters,” the second “shingles and skin rash,” and the last “thrush in the mouth and throat.” The photos are preceded by a list of AIDS-related symptoms, presented as a rhetorical question: “Is someone in your family suffering from [list of symptoms]? They are! Then they need Hi-Vite to boost their chances of fighting their infections.” A cell phone number and e-mail address are provided. Like the other products described above, HI-Vite claims to bring together indigenous knowledge and biomedicine. The cocktail’s ingredients include, among other things, the African potato (known for its supposed effect as an immune booster), selenium, various minerals, and amino acids.

In the support group that Ntombi attends, not everyone has been systematically exploited in these trading networks. Some members have taken advantage of the system and have assumed more active roles as volunteers. They attend clinics outside their own areas to counsel patients. They then collect medicines for their own use or for their relatives to alleviate the chronic lack of supplies in their own area. The turn to new cures available in the city may result from a family member’s initiative as well as from financial constraints. Adelina, a young HIV-positive woman, was taking AZT (Zidovudine, an antiretroviral medication) at a cost of R700 per month. This expense was covered by Adelina’s aunt, a domestic worker for a white family in the north of Johannesburg. After one year of treatment, Adeline was advised to switch to a tri-therapy treatment, but this was very expensive and her aunt could no longer finance it. Adeline’s aunt advised her to go to the center of town to see an Indian doctor whom she knew who practiced Ayurvedic medicine. While not trying to cure her but simply to improve her general condition, this doctor prescribed a treatment based on roots and herbs that brought the monthly cost down to R125. Satisfied with this medication, Adelina is still taking it. She has also joined a support group in Alexandra where she provides home care as a volunteer.

---

16. Tri-therapy treatment attempts to reduce the level of viral load in the body for as long as possible in order to maintain the strength of the immune system. It is a combination of three antiretroviral drugs, usually a combination of one or two transcriptase inhibitors with one or two protease inhibitors. For more information on HIV and AIDS, see Evian 2000.
Vast, anonymous, inscribed in the exchange of goods on an international level, and also caught up in a local epidemic and ideological context, Johannesburg allows individuals to invent their own cures. Cosmopolitan, it makes accessible all kinds of avenues, from Ayurvedic medicine and Chinese green tea, said to prolong life, to antiretrovirals sold in the offices of private doctors. While exploring these networks, or by creating them, sufferers cross the urban boundaries between rich and poor, black and white, and travel across the townships, the city center, and the northern suburbs. The area clinic and the hospital are the initial range of any exploration of the city. This circle then enlarges to include other clinics and other hospitals. Ever alert, patients take advantage of any opportunity that presents itself. These inscribe sufferers, often without their knowledge, in national or even global contests, both ideological and financial, and make them vulnerable to exploitation. The city, however, is creating the conditions for political mobilization, allowing people to exist not only as suffering bodies but also as political actors.

The Open City and the Creation of a Civil Society

For many people living with HIV/AIDS, the urban experience encountered on the edges of the townships is inscribed in wider life histories that often begin outside the city. Such is the case of Jesus and Elsy. After failing his final high school examinations in 1991, Jesus, originally from Limpopo (300 kilometers north of Johannesburg), decided to come to the city to try his luck. As he notes, “Egoli is still the city of gold.” Jesus stayed for a while with a cousin, who worked as a houseman for whites living in Rosebank, and enrolled in a commercial college with the financial support of an older brother working in Limpopo. One year later, he found a job in Mayfair at an Indian-owned factory. There he met a young woman and moved in with her. He quickly discovered that she was a prostitute in Hillbrow, close to the city center. They stayed together for a while, and then one day she left, without a trace.

Elsy, meanwhile, left Kwazulu-Natal to escape a stepfather who was abusing both her and her sister. She joined an aunt living in Johannesburg, who found her employment as a domestic worker in Mayfair. Elsy used to go to a shebeen near the Diplomat Hotel and Tavern 702. She also used to visit the park near the police...

17. Egoli is the Zulu name of Johannesburg and means “city of gold.” This name was given to the city in the nineteenth century, when working in the Johannesburg gold fields was the only way for rural migrants to earn money. More than one hundred years later, the city still attracts rural migrants, for the same reason.
station to eat lunch or to have her hair done. Elsy and Jesus met each other in a local supermarket and started living together in a flat in Yeoville that they shared with some of Jesus’s friends. In 1993, this group of friends took AIDS tests, out of bravado more than anything else. Elsy and Jesus were found to be HIV positive. They did not really pay much attention, however. In 1997, it became difficult for them to share a flat with friends, and Elsy decided to buy a shack for R1,000 in Alexandra. She and Jesus moved in together. In the meantime, Elsy left her job as a domestic worker. She bought fabric at the Indian Oriental Plaza in Fordsburg and in President Street in Newtown and started making and selling cushions. In 1998, Elsy gave birth to a little girl who died nine months later at the Johannesburg General Hospital in Parktown. It was then that Elsy and Jesus fully recognized the significance of their HIV status and became involved in new networks—those of treatment and support.

Jesus and Elsy put together their meager funds and asked for contributions from friends and acquaintances in order to bury their daughter. The whole experience proved too much for the couple, and they separated shortly afterward. Jesus stayed with various friends until he found a place at a Protestant mission in Soweto that was about to open a hospice for HIV/AIDS patients. After staying there for several months, during which he served the mission by developing contacts with various sponsors, Jesus decided to leave Johannesburg and go back to Limpopo, where he married and put his efforts into AIDS prevention. Elsy stayed in the shack that she had bought and became a volunteer caregiver in a support group for those living with HIV/AIDS.

She subsequently attended the HIV clinic at the Johannesburg General Hospital in Parktown for treatment for herself and for the child she was expecting by another HIV-positive boyfriend. The clinic provided her with Nevirapine (a product given to pregnant women or to newborn babies that reduces the risk of mother-to-child transmission of the virus). After her baby was born, Elsy continued to attend the HIV clinic, working as a volunteer counselor. This work enables her to supplement her disability grant by an extra R800 per month. In addition, her presence at the clinic allows her to take advantage, when necessary, of personalized care. In fact, volunteers and employees are often included in therapeutic trials, thus giving them free access to antiretroviral drugs that would otherwise be available only from a private doctor—and hence financially inaccessible.

18. This work is considered volunteering, though people do receive a stipend after they have shown themselves to be committed to the work. However, the stipend still falls far short of a living wage. The volunteers often view it as a temporary income or a step toward a salaried job in the field of health care.
Voluntary work is not restricted to searching for sponsors and funding but also implies a learning process for people who left school long ago. In order to become a volunteer, Elsy attended a training course with the Gauteng Department of Health in the city center of Johannesburg. This was the first time she had gained access to an official building. Shortly afterward she took a job with an organization for AIDS sufferers, the Treatment Action Campaign (TAC), whose offices in Johannesburg are situated in Braamfontein, which is close to the city center. Through her involvement in this association, Elsy is gradually obtaining social recognition not only as an HIV-positive individual but also as an actor in the affairs of the city. The TAC plays a militant role in the fight for a national program that would provide general access to antiretrovirals. As part of her work for the TAC, Elsy participates in public information campaigns and in other actions directed at political figures or at the public health service. She moves from meetings in Braamfontein to participation in actions in Pretoria or Johannesburg. She also takes part in various meetings and lectures, which have given her the opportunity to travel to Durban and Cape Town for the first time. These journeys are paid for by the TAC. During the campaign of civil disobedience organized by the TAC in 2003, Elsy, along with others, protested a speech given by Minister of Health Manto Tshabala-Msimang at Public Health 2003—a conference held on March 25, 2003, at the Eastern Boulevard Holiday Inn. The following day, an article entitled “Activists Give Health Minister the Boot” appeared in the Star, a daily newspaper. The press’s favorable response to these actions confirmed Elsy’s feelings: because of her involvement in this movement, she is being “taken seriously.”

Strengthened by this new legitimacy, Elsy is claiming her rights and carrying with her other HIV-positive individuals. If legal advice or support is needed, she accompanies them to the AIDS Law Project at the University of the Witwatersrand—a group that is seeking to establish legal precedent in the area of HIV/AIDS-based discrimination. There, they have access to pro bono legal counsel, and they are given the opportunity to expose and condemn the abuse to which they are subjected. Elsy also visits the AIDS Consortium, which is found in the same district—Braamfontein—and which is the central organ for information on AIDS.

The TAC benefits from strong international support, of which its members, such as Elsy, are well aware. The NAPWA (National Association of People Living with HIV/AIDS) does not have the international profile that TAC enjoys. However, it does offer HIV-positive people the same room for mobilization on a national level. Each uses the network of support groups and takes advantage of its
accessibility across the city. This was the case in April 2002, when a group of people, all HIV positive, visited Johannesburg support groups to collect the number of signatures required to create the HIV Support Party. The cell phone may be a fashion item and status symbol, but it is also a vital instrument of socialization for members of these networks. Individuals are able to keep in contact via SMS (Short Messaging Service). They are informed of events that they might want to participate in, from workshops to burials of AIDS victims. The purchase of a limited amount of airtime allows them to send an SMS to someone with more funds in order to be contacted. It is not unusual for the first disability grant payment to be used to buy a cell phone.

The Final Station

Increasingly, the members of support groups are openly participating in the funerals of their deceased members. It is common to see militant members of AIDS organizations at these funerals. These actions are part of a movement to eliminate the stigma around the disease, a movement that can be seen at burials in Johannesburg and surrounding areas. Instead of attending anonymously, the members of the support group display red ribbons, which they also distribute to those present. Some of them wear TAC or NAPWA T-shirts. When the funeral convoy leaves the home of the deceased to go to the church or the cemetery, the hearse is preceded by the members of the support groups.¹⁹ Just as during the struggle against apartheid, they sometimes *toyi toyi*.²⁰ They also sing religious songs and chant slogans promoting the use of condoms. These demonstrations are not limited to the funerals of active members of associations of AIDS sufferers but are also organized for ordinary support group members who request them before their death.

At the cemetery, the support group members generally form themselves into a separate choir, as do work colleagues if there are any present. At funerals for people whose HIV status is known, it is not unusual for an anti-AIDS sticker to be affixed to the coffin. It could just be a simple red ribbon or sometimes a red ribbon on a blue background with the question "I care, do you?" It is at this final event that the city welcomes, in its very depths, the body that has traversed and

¹⁹. After a ceremony at home, the bereaved go directly to the cemetery or they go via a church or temple, depending on the religious affiliation.

²⁰. *Toyi toyi* is a demonstration in which the participants form a compact group, stamp their feet, and chant slogans—something that came to symbolize the struggle against apartheid in the townships.
crisscrossed it. A body or a human wreck—it no longer matters. The death of an AIDS sufferer has an ambivalent effect on the support group. It reinforces the unity of the group by mobilizing its members around the deceased and provides an example, to those who are left, of the quality of the escort provided by the support group members. Ntombi (the young, HIV-positive woman living in Alexandra discussed above) reported that she could not stop thinking about her own funeral during a huge *toyi toyi* at the burial of an Alexandra woman. She imagined it would follow the same pattern. The thought of a close and unavoidable end is also expressed in the bodies of those members of the support group surviving the deceased. They often complain of falling ill and suffering from diarrhea as a result of stress at the thought of their own deaths.

**Conclusion**

The metropolis that emerges from the journeys of suffering HIV-positive bodies living on its periphery is both visible and invisible. Initially, it is structured by official AIDS sites at various levels. Support groups, clinics, hospitals, and social service agencies constitute the emerging part of this structure. Here the epidemic is overt and measured (the number of patients testing positive, the number of volunteers trained and supervised). However, the patients’ search is not restricted to the public sector. It also extends to the unofficial paths of treatment and resources. And here the city becomes hidden. The city submerged in suffering bodies begins in the domestic sphere, where the sick retreat or hide; it then extends to the churches attended by sufferers and includes the illicit AIDS networks that lead those living with HIV/AIDS from therapeutic trials to the sale of unauthorized products—sales that exploit the lack of an official response to the treatment of AIDS. This city is drawn in dots. An exploration of the networks of people living with HIV/AIDS clearly does not exhaust the question of how the metropolis is experienced. However, it does reveal a part of the essence of urbanity. Local and global, the metropolis inscribes the sick, who maneuver within these networks through exchanges and debates that go beyond the city itself. The links between sufferers, product distributors, and organizers of therapeutic trials are made not on the basis of linear, rigid networks, but on the basis of encounters that are sometimes random, sometimes orchestrated—opportunities that by nature do not last.

The quest of the sick does not acknowledge the administrative health divisions of the city but follows the principle of a search for optimum care. This quest transcends the suburbs of the rich or poor, black or white, just as it transgresses the
rules of a medical system that sends patients from one health center to another higher up the chain. It involves journeys that are as much a function of an individual’s state of health (the body is finally forced into immobility) as his or her financial resources. In this context, mobility is not a temporary state but—for the poor population living on its periphery—the very condition of survival in the city. This mobility consists of coming and going, incursions into the official city and retreats into the city of the poor, frozen in its suburbs and impermeable to the daily life of the sick. Johannesburg appears simultaneously as a space whose resources may potentially be exploited but also as a dangerous place where suffering remains largely invisible, despite the Department of Health’s slogan reproduced over and over again on T-shirts and stickers: “I care, do you?”

There can be no place more poignant to ask this question than the cemetery. Today, the cemetery in Alexandra is full. Families are now being advised to bury their deceased in Midrand, an hour from Alexandra. Once the ceremony is over, it is no longer the disease that hinders visits to the dead but the financial resources needed to make the journey. The frequency with which individuals attend burials of members of their networks is a reminder of the brevity of their own existence. As for the city, it is clearly in its nature to survive its dead. But the city hardly exists without this submerged component, the depths in which the scraps and the remains finally come to rest.

Frédéric Le Marcis is a researcher at the Center for Research on Contemporary Issues in Public Health (CRESP), a research center affiliated with the Université de Paris Nord, the École des hautes études en sciences sociales, and the French Institute of Health and Medical Research (INSERM). He is also a research associate in the Department of Anthropology at the University of the Witwatersrand.

References


