

Part Four

Facing the Challenge of HIV/AIDS

Choosing Between Life and Death: Rationing of Health Care During the AIDS Epidemic in South Africa

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In the year 2000, our book, *AIDS Doctors: Voices From the Epidemic*, was published.¹ By that time, the relative therapeutic impotence of the first fifteen years of the epidemic, at least in North America and Europe, had drawn to a close as powerful antiretrovirals became the standard of care. *AIDS Doctors* was an oral history that sought to capture an important perspective on the course of the HIV outbreak in the United States before it was lost. It aimed to preserve the memory of a long and dreadful period for those who might come to look back, uncomprehendingly, on what it was to be a doctor in that country, caring for those afflicted by AIDS. Our central goal was not to gather new facts, although we did so. It was rather to use oral narrative to write the epidemic's history, to tap each doctor's subjective sense of events and to elicit the meaning that he or she found in them. Our approach allowed doctors to address the professional, personal, political and ethical issues the epidemic raised for them. The result was a collective biography, a two-decades-long story of the experience of a minority of doctors who committed themselves to treating patients with a new, stigmatized disease.

2000 was also the year that the International AIDS meeting was held in Durban, South Africa. The light it shown on the epidemic in that country was shattering. Although there had been an earlier outbreak of AIDS in the gay communities of South Africa, from the mid to late 1990s a massive heterosexual epidemic had taken hold. This was a bitter irony, since it was in 1994 that South Africa had finally liberated itself from apartheid. Worse, the epidemic revealed the social and political fault lines of the post-apartheid state. We came to believe, at that moment, that a new oral history project, one that captured the full experiences of both doctors *and* nurses working within the epidemic in South Africa was crucial.

¹ Ronald Bayer, Gerald Oppenheimer. *AIDS Doctors: Voices From the Epidemic* (New York: Oxford University Press, 2000).

As we had in the United States, we identified a number of key informants, primarily South African, who provided us with lists of doctors and nurses who had been working for some years with patients infected with the HIV. Those clinicians, in turn, gave us additional contacts. In all, we came to interview close to ninety doctors and nurses across South Africa, from urban centers like Johannesburg, Cape Town, Durban and Pietermaritzburg and rural clinics in places like Tugela Ferry and Lusikisiki.

Over the past decade, a substantial literature on the South African AIDS epidemic has begun to emerge, largely written by epidemiologists like Salim and Quarraisha Abdool Karim² and social scientists like Alan Whiteside,³ Nicoli Nattrass,⁴ Mary Crewe,⁵ Helen Schneider,⁶ Virginia van der Vliet,⁷ Loveday Penn-Kekana,⁸ and Charles Becker and his colleagues.⁹ A few, like Philippe Denis,¹⁰ have tapped oral history techniques. None, however, have had as his or her central purpose to write the history of the epidemic from the perspective of health workers at the coal face.

Our interviews were guided by a series of broad questions that sought to trace the experiences of each person we interviewed, but remained open to areas of inquiry that we might not have anticipated. Perhaps the most distinguishing feature of the interviews conducted in the United States was the recognition of the need to remain attentive to the political context within which the AIDS epidemic was unfolding. In South Africa that social matrix was even more critical, particularly the existence of vast inequalities in access to health, the subtle and not-so-subtle legacies of the apartheid regime, and the scarcities that shaped so much of the South African health care system.

This chapter is drawn from our book, *Shattered Dreams? An Oral History of the South African AIDS Epidemic*, to be published by Oxford University Press in spring, 2007. This book will reflect the scope and depth of our interviews with South African health workers.

Rationing of medical resources, therapeutic interventions, and life itself is a fact of life in South Africa. Reflecting both resignation and a pragmatic determination in the face of scarcity, a young doctor working in a remote rural area of KwaZulu-Natal said,

I have always worked in a framework where I assume that there aren't enough resources. For me it has always been ok, how can we find a solution, rather than becoming indignant.

² Quarraisha Abdool Karim, Salim S. Abdool Karim, Bipraj Singh, Richard Short, Siphon Ngxongo, Seroprevalence of HIV infection in rural South Africa. *AIDS* 6/12 (1992), 1535-1539.

³ Alan Whiteside and Clem Sunter *AIDS: The Challenge for South Africa* (Cape Town: Human and Rousseau Tafelberg).

⁴ Nicoli Nattrass, *The Moral Economy of AIDS in South Africa* (Cambridge, Cambridge University Press), 2004

⁵ Mary Crewe. South Africa touched by the vengeance of AIDS: responses to the South African epidemic. *South African Journal of International Affairs*. 7/1 (2000), 23-38.

⁶ Helen Schneider, Joanne Stein. Implementing AIDS policy in post-apartheid South Africa. *Social Science and Medicine*. 52 (2001), 723-31.

⁷ Virginia Van der Vliet, South Africa Divided Against AIDS: A Crisis of Leadership. In Kyle D. Kauffman and David L. Lindauer, eds. *AIDS and South Africa: The Social Expression of a Pandemic*. (Houndmills, UK: Palgrave Macmillan, 2004), 48-96.

⁸ Loveday Penn-Kekana, Chronique hospitalière. Les professions de santé à l'épreuve du SIDA. In Didier Fassin, ed. *Afflictions: L'Afrique du Sud, de l'Apartheid au SIDA*. (Paris: Éditions Karthala, 2004), 39-159.

⁹ Charles Becker, Jean-Pierre Dozon, Christine Obbo, Moriba Touré, (eds.) *Vivre et penser le Sida en Afrique* (Dakar/Paris : Codesria/Karthala/IRD, 1999).

¹⁰ Philippe Denis, Nokhaya, Makiwane. (2003) Stories of love, pain and courage: AIDS orphans and memory boxes. *Oral History*. 31/2 (2003), 66-74.

The reality that defined his work was shaped by the current lack of resources and the legacy of apartheid. The health care system in South Africa is mixed, consisting of a private and public sector. Physicians in the private sector serve the needs of the privileged, defined in terms of relative and absolute advantage. Those employed in the under funded public sector treat the poorest, medically neediest population. Ten years into the post-apartheid state, class and race still define who shall be cared for, and influence who shall live and who shall die.

While those providing medical care in many less developed nations compare their impoverished health systems to what exists in wealthier countries in the global economy, in South Africa such radical differences exist within the confines of a single society, usually within the same city. In a nation formally committed to razing apartheid's institutional legacy and creating a social democracy after years of bitter liberation struggle, these enduring differences have become inequities gnawing at the foundations of the new order.

In this paper we examine the rationing of health care and life itself for those with HIV in South Africa, a nation with more than 4 million infected individuals. We explore this issue through the eyes of doctors and nurses who have been involved in the care of infants, children, women and men burdened by AIDS and AIDS-related conditions. This account is based on more than eighty-five interviews conducted in South Africa between January 2003 and January 2004. Those we interviewed were identified by AIDS experts in South Africa or through "snowballing" techniques. They were Black, white and Indian. They worked in hospitals, vast institutions like Chris Hani Baragwanath Hospital that has always served Blacks living in Soweto, or integrated institutions that had historically served only whites. A number tended patients in former mission hospitals that retain the religious ethos of their provenance. There were private practitioners whose rooms were as elegant as those of doctors in Europe or America. Others provided care in spare, cramped quarters. Some clinicians we interviewed treated patients with substantial private resources or with medical insurance, some the unemployed and impoverished. A number of doctors and nurses we spoke with were employed by AngloGold, a mining conglomerate. Our interviews, which lasted two to three hours, used a set of open-ended questions to which individually tailored queries were added. Interviewees were asked to be as frank as possible and were promised the opportunity to review, amend and approve their transcripts before they would be used in a way that could serve to identify them.

I.

The AIDS epidemic in South Africa both highlights and magnifies the clinical and moral problems raised by medical rationing. When resources are limited, either because of policy decisions or absolute scarcity, who should be offered care? What moral judgments, clinical assumptions, medical evidence inform such decisions? Should the rules of rationing be explicit or implicit? Should such norms be applied in an invariant "objective" fashion or with a degree of flexibility? Should rationing be blind to the exigencies of patient differences or should the claims of real people bend the rules? Such questions had to be addressed as an unparalleled epidemic threat exacerbated already difficult conditions.

One of our informants portrayed the growing chaos as a rising tide of patients suffering from AIDS sought admission to a public hospital in Durban in the late 1990s:

People used to be coming in on stretchers from all over the outlying areas absolutely sick, dehydrated, vomiting, hardly able to breathe, and their entire communities used to come along with them. APlease help this person; do something.@ And there was no mechanism in that hospital to

take these patients in, to sort them out medically, to equip them with the knowledge and the means to go back home and take care of themselves. The hospital was so overwhelmed with the numbers of these patients that the basic minimum was done and they were asked to go back home; that was a terrible thing.

A doctor at Chris Hani Hospital described how patients had begun negotiating for hospital beds:

The fact that you are HIV infected now is that you can hardly even get into this hospital. You get turned away at casualty. When it started, people would spend a lot of time investigating HIV infected people. There would be a time when there would still be admission to the ward, but they wouldn't get the best care. Now there is a time when you can't even get them into the hospital.

However many people with AIDS were turned away, the sheer number applying meant the wards began to fill with such patients. In fact, careful analyses have suggested that despite increasingly crowded conditions, with "floor beds"—blankets under beds -- to accommodate the overflow, it was those with HIV who were pushing out other patients.

Having gained admission, AIDS patients encountered limited treatment, often bordering on neglect. Implicit or explicit beliefs that people with HIV-related conditions represented a sink hole informed such behavior. In the words of one of our doctors, the common stance was, *Why treat these patients? They are going to die anyway.* While many doctors and nurses spoke with bitterness of the refusal of colleagues to provide particular medical interventions to patients solely because they were infected with HIV, even the most sympathetic could be filled with doubt. As a physician at King Edward Hospital in Durban recalled:

The patients would come in with tuberculosis (TB) [first occurrence of TB...] and then you would treat it. They would come in with PCP (to develop...: *Pneumocystis carinii*...) and we'd treat it. But then they would develop cryptococcal meningitis; we tried to treat it and 70% never left the hospital alive. You watched your patients die. And then, for a year or two, I went through this phase where I said, "Is it worthwhile treating these patients, because they are going to die in any case." And we felt we were beginning to deprive the health care system of resources; in other words, pouring it down the hole and getting nothing in return. And I took the view that patients with advanced AIDS shouldn't be treated. They should be offered hospice care; and those who were pre-terminal should be sedated because it's not nice to see them suffer.

Indeed, gripped by a sense of the futility of treating AIDS, physicians embraced the argument that a fair and just health care system required the husbanding of resources. A failure to ration care meant that others who might benefit would be deprived of life saving treatment. The systematic exclusion of people with HIV from intensive care units at many public hospitals seemed a reasonable choice, given the alternatives. There were precedents. One pediatrician viewed the restriction of care to people with HIV through the lens of his neonatal experience:

There was an issue of premature and low-term babies. I was dealing with this on a daily basis. AIDS wasn't very different. I was very straightforward with parents, basically saying we have limited resources, twelve ICU beds; mother, if the baby doesn't improve, we are going to withdraw care. That was my own method of dealing with it. It wasn't the matter of should we or shouldn't we take your baby off the ventilator...or shouldn't we send your child with HIV to the ICU. It was a matter of fact. We are doing this. I think most parents will accept that because in the kind of environment we worked in, the doctor was God.

A doctor in a public hospital in Cape Town defended the exclusion of some AIDS patients from the ICU as long as that policy was categorical and supported by clinical data:

Our intensive care unit has now made an explicit policy that they will not admit people with [pneumocystis] pneumonia into the ICU (Intensive Care Unit). I think that's not unreasonable given that they have very limited facilities. They had looked at all the mortality for other diseases, around 20%. They'd looked at their own pneumocystis experience, and it's around 60%. That's not a good use of resources. So they have decided to exclude that group of patients, and I don't have a problem with that, as long as it's explicit. I quite like that very recent trend in rationing we now have. People are saying they have done the same thing for head injuries in this hospital.

But that same physician admitted that his own hospital provided expensive, technically demanding, high risk therapies to patients with diseases other than AIDS; AIDS was, in fact, perceived as different:

AIDS, it's not like other diseases. This hospital does cardiac, liver, renal, bone marrow transplants. We use almost all the drugs that you would in the United States to prevent rejection. We do dialysis. So expensive therapies are available here, but not for HIV. So there's that injustice; that is very hard.

Restriction on access to the ICU could nevertheless coalesce into rigidity, applied even once clinical justification no longer prevailed. What was earlier taken as just could then become unreasonable, an act of invidious discrimination. A doctor working at Chris Hani Hospital in Soweto recalled:

We managed to get some kids onto anti-retroviral therapy. These kids were on triple therapy and had reasonable clinical prospects. But on occasion they would require ICU. And I would phone the head of the ICU and say this child should go into the ICU because this child was on triple therapy and had a good prognosis. And they would not let the kid in because the kid was HIV infected.

Although there is evidence of explicit decisions to ration care, buttressed by reasoned arguments and data, in most instances restrictions on access to care seemed to emerge organically, without careful thought, most often a consequence of structural forces, the lack of resources that affects much of South Africa's public medical sector. As one pediatrician in a public hospital noted:

I think there has certainly been evidence that care has been rationed to HIV positive children, as it is to adults. Some of our colleagues did present figures that showed that the average stay of an HIV positive child is less. Certainly HIV positive children are getting less care. They are being discharged earlier because people feel that there is nothing that they can do. I don't think it's been a conscious policy decision; it's just been the way that people cope with the numbers and the reality of a busy African general hospital. I think it's the wrong decision. But the solution to the problem is not going to come from individual doctors or individual hospitals. It's going to come from a policy that provides comprehensive AIDS care as it should be provided.

Many who were troubled by the assumptions behind rationing health care for HIV infected patients, inveighed against the ignorance of their colleagues who equated AIDS with death. Fatalism, they believed, whether given voice in a language of despair or high toned stoicism, was unwarranted. Speaking of the care of AIDS patients, one private physician recounted:

Our colleagues say, "Oh, no, there's nothing I can do for you." I know of a circuit HIV 'expert'. The brother of a patient of mine is being treated by this man. She phoned him up to say, "He's getting very thin. I'm worried about it." And the 'expert' said, "Well, what do you expect?" She asked, "Is there nothing we can do?" "Why bother doing anything? He's going to die one of these days anyhow." I was absolutely horrified. I had her bring him [to me] because that mentality is absolute bullshit and I'm not going to accept it.

Thus the impulse to deny care might reflect inadequate knowledge about how opportunistic infections could be treated and about the prognosis of patients who receive appropriate care. Strikingly, such ignorance has characterized not only those who had finished their medical training before AIDS emerged as a defining issue for the health care system of South Africa, but also those who completed their medical education well into the epidemic's development. Speaking of the students who came to Chris Hani Baragwath Hospital as late as 2003, a physician noted:

The level of knowledge [about AIDS] I find in medical students who have been at medical school for four, five, six years, because that's when we see them, is absolutely appalling. I don't think they are actually learning anything, and that is very frightening. Again, it's partly been an attitude within the medical department and the internists that they have no drugs, they can do nothing; this is getting in the way of what real medicine should be like. And, unfortunately, medical students are taking that on board. Doctors who graduated in the last five years know very, very little about HIV.

As a consequence of such therapeutic nihilism, fatalism and growing exhaustion before the waves of HIV cases, doctors often made presumptive diagnoses that justified inaction and deprived patients of life-extending, medically appropriate services. One of our informants spoke of a case in one of her wards:

There was a child whose encephalopathy they just attributed to HIV. And I was outraged. I said, "But you haven't investigated this child. This child could have TB meningitis; it could have anything. Why haven't you done a lumbar puncture on this child?" So what happened was that people stopped investigating children with HIV; they wouldn't bother making sure that they had covered all the different angles.

Most telling about the attitudes that pervaded public hospitals in the mid to late 1990s was the resistance on the part of many hospital administrators to the establishment of special clinics designed to meet the needs of those with AIDS. They looked upon AIDS with oceanic indifference. Speaking of two public hospitals in Pietermaritzberg, a doctor asked:

What was the activity for the problem of HIV? There was nothing, absolutely nothing. There was no HIV clinic in Grey's Hospital [which had historically been a white hospital], at Edendale [which had served Blacks during the apartheid years]. There was a Rumanian lady who tried to do something, something with nothing. Nobody was supporting her. Nobody was giving her help. The venue she was working in was terrible. Eventually she got another place which was even worse. All that she was doing was not respected.

At Chris Hani Hospital, the pediatrician who established a clinic for children with HIV and their mothers was told when she left on sabbatical that the clinic would be closed until she returned. No administrator or clinician would step forward to assume her responsibilities.

How did the limits on care affect those who had not sought to turn their backs on AIDS? Those who stayed in a public sector so overwhelmed by the epidemic or who in the context of private practice developed large AIDS caseloads? For some the only option was an emotional distancing that made the suffering of their patients easier to endure. Working in a rural hospital, a doctor, acutely aware of the epidemic's traumatic impact on him, recounted:

What I find quite difficult is that so much death is anonymous. The people come in. They are moribund and die the next day. Families bring people in; they have got severe thrush and they are emaciated, they have got diarrhea and like three or four days later they die...It's a flood difficult to engage with ...It blunts us to treating people very carefully. You almost don't want to know. You don't want to engage with it because engaging with it makes you tired, makes you exhausted. You have heard it so many times and it's not interesting anymore or stimulating. You don't want to know about another person's pain. So often two o'clock in the morning, when you are tired, they would come in. I mean, this person has been like this for how long and now you come in at two in the morning? Why are you wasting my time? It becomes very difficult then to start to say "So what does it feel like?" Actually, I don't care. I don't give a fuck. It gets too much. You don't want to engage with it; it's not important.

Another fact that makes such distancing possible, often precluding intimate contact with patients, is the barrier of language. We were struck by how rare it was for white and Indian doctors to speak anything more than a few words of any African language. They frequently told us, "It's just too difficult," "I'm not a linguist, I've tried," "I should, but I don't have the time." Although apologetic, doctors seemed relatively untroubled by the fact that they couldn't develop a direct relationship with those they treated, but depended upon a third party--a nurse, a clerk--to communicate with their patients. That this was so, even among the most committed of doctors, must be seen as a legacy of apartheid.

The inability to share a common tongue between doctor and patient certainly makes implicit and explicit rationing psychologically easier. The patient remains "the other." One of our doctors was especially sensitive to the issue, having forced himself to learn Zulu:

I wanted to speak Zulu because I wanted to know what was being said. Once I started to understand Zulu, I realized that there's just mountains that gets lost in translation. And for me it's one of these things that prevents me from blunting; it helps me to engage with the person. I think what's quite interesting is that a lot of patients want to see me because I speak Zulu, especially if I've seen patients before. They often want to come back to me.

Understanding Zulu was instrumental in moving one influential Indian doctor in Durban from a cool and reasoned position of therapeutic nihilism and resource rationing to a defense of active clinical intervention:

What I began to see happening around me was a sense of hopelessness amongst the medical staff. In the minds of the junior doctors, they were beginning to question, what the hell am I doing here? If 80% of your patients have AIDS and you can't do anything, what am I as a doctor? What really turned me around was one incident, where I was doing rounds with my team. We came to one patient. We discussed his cardiac problem, discussed treatment, spoke to the patient. I saw the next patient and then told the person, no to that patient. I knew he had advanced AIDS; there is nothing you could do, and we skipped him. I understand Zulu, so that patient told the patient next door to him, "I wonder why the doctors don't want to see me today. I think I am going to die." I heard this and froze in my tracks. I suddenly realized that the patient is right; this is the message I sent him. In my heart I knew that was the reality, but what I took away from him was his hope. I immediately realized that was wrong. I had to just stop there and greet him; it wouldn't have taken

long. I came to my office and I sat down there, and I think I must have shed a tear or two, and I realized that if this is what I am doing as a doctor, then I am in the wrong place. I must either leave the system or do something about it. And so increasingly I started getting involved and sort of looked around to see what opportunities there are for anti-retroviral treatment.

II.

In 1994 when the HIV epidemic began its catastrophic escalation in South Africa, but when the number of clinical cases was still relatively small, the global picture with regard to anti-retroviral therapy was grim. The Concorde trial in Europe had demonstrated that AZT, the first anti-retroviral drug used in the AIDS epidemic, was relatively ineffective. A common bond united the richest and poorest nations. In neither was it possible to combat the underlying course of the cascade of disease that afflicted people with AIDS. But in 1995 that began to change. The first reports about a new class of drugs – the protease inhibitors – indicated remarkable efficacy. By 1996 an air of triumphalism characterized the International AIDS Meeting in Vancouver, Canada. Triple combination therapy was shown to reduce viral loads to undetectable levels. Patients were snatched back from the edge of death. But these therapies were extraordinarily costly. And thus did the global divide begin to define the AIDS pandemic. In rich nations, AIDS was increasingly viewed as a manageable, chronic, if ultimately still fatal disease. In the world's poorest nations, where the epidemic dwarfed the burden in the industrialized world, the therapies were all but inaccessible. Rationing by ability to pay came to define the global world of AIDS.¹¹

In South Africa, the cost of the new drugs, of HAART – Highly Active Anti-retroviral Therapy – seemed utterly out of reach. But to some private practitioners, especially those who had been involved in the care of gay men in the early and now all but forgotten first South African AIDS epidemic in the mid 1980s, it was possible to prescribe the new treatments. Within private sector medicine, some small number of patients could thus begin to reap the benefits of the new scientific achievements. And so in South Africa, the gulf that had always characterized the privileged and the masses was given a new expression. Those who could afford treatment would live. Those who could not would die.

Even as the price of drugs began to decline at the end of the 20th century and in the first years of the 21st – as a result of political pressure on the pharmaceutical industry and as a consequence of competition from the generic manufacturers – and as private medical insurance began to cover the cost of anti-retrovirals, those who could afford the life saving treatment remained small. Within private practices and in hospital settings, some could purchase drug treatment, most could not. Rationing medications by the ability to pay became the norm in South Africa, especially since the government of President Thabo Mbeki has refused until recently to fund anti-retroviral treatment in the public sector. Private physicians were forced into the uncomfortable position of having to gauge what their patients could buy and into the morally difficult role of having to limit what they could offer. One of our doctors, a Christian woman working in a historically Christian hospital, described her sense of sorrow and paralysis:

¹¹ See the conclusion chapter and the synthesis by Jean-Pierre Dozon : “ *From the social and cultural appropriations of AIDS to necessary political appropriations : some elements towards a synthesis*”, 689 & ss, in Becker Charles, Dozon Jean-Pierre, Obbo Christine, Touré Moriba (éds), *Vivre et penser le sida en Afrique / Experiencing and understanding AIDS in Africa*).

It is horrible. It is very hard when you know that there are people that do get good care. There are many gaps in care because of cost factors. Your heart breaks sometimes when you know if they had anti-retrovirals they could carry on bringing up their children. They could carry on, and you know they are not going to. It is heartbreaking when you know that there is something that can be done, and you actually can't do it.

The most compassionate doctors were paradoxically forced to spend time teasing out financial information, feeling out what patients could afford without adding further to their emotional burdens. Working in a public hospital in Pietermaritzburg, where some patients had the ability to draw on personal or family resources, one doctor noted:

It would be possible to ask a sister to have a talk with the patient explaining the anti-retroviral drug and the cost. But it has not been my approach. When we see a patient for the first and second time, we have a questionnaire, so we have some information about the job they are doing, whether they are working, do they have some income, who's taking care of them financially. We also look at how they're dressed, and so on. When the feeling from the information is positive, then I start to ask what the maximum amount of money would be that they could afford per month for treatment. Often they say it will have to be a small amount, because they cannot imagine what it will cost. When they have said that amount, I try to increase it to see if it would be possible. We try to find if the patient will be able to say yes or no.

Under these circumstances, plumbing a patient's finances and those of his or her family could be torturous for any doctor or patient:

It is very difficult. You don't want to miss someone who could afford ARVs; and you do not know if there is someone who might have an uncle, or if the family all got together they might be able to rustle up the money. So it doesn't feel right for people not to know in case they can afford it. But to tell someone there is something that you can do, I always say in the beginning it is very expensive and most people can't afford it; that is how I start. So at the very beginning they don't have this hope, this total hope. But this girl, we talked about it, and she said she cannot afford it, and she cried. You sit there and can just cry with them really, because there is nothing I can really do.

For some the encounter with inequity was simply a fact of life. They could do little to resolve the problem within the limits of the clinical context. The result could be the equivalent of a moral shrug of the shoulders. Others took refuge in their Christian faith, shepherding each patient through his or her illness:

It is very hard to have people coming in and you know that this is their chance and they cannot afford it. You just have to take each person as they come. The whole person sitting with you in that room is the person you are concentrating on, giving a handle on what you can do that's going to help them best in the situation they're in. You can't be comparing all the time. When the people can afford anti-retrovirals, and they come back a month later, and they put on five kilograms, and they are grinning from ear to ear, it's really exciting and you rejoice with them. But when the next person comes in, and there is nothing that you can do because no one can afford it, then you have to just work out what's best for that person. If they need to go to a hospice, organize a hospice. If they need their family to be trained for home care, do that. You have to take each person as an individual and do the best you can under the circumstances.

In the end, taking refuge in her belief in an after life, this committed physician was able to say "life is not everything."

III.

For those who resisted such resignation and for whom the limits imposed by the cost of drugs were intolerable, one alternative to rationing by ability to pay was to undertake clinical trials that could provide at least some of their patients with access to anti-retrovirals. Said one clinical researcher in Cape Town “We try to squeeze [our patients] into clinical trials.”

For international pharmaceutical firms, poor, drug-naïve South Africans represented an ideal population for research. As one doctor observed, “We had tons and tons of patients who had never smelt ART, so that we could get the numbers up very fast, and we were a cheap place to do research.”

Such trials benefited both patients and doctors:

I have been involved in a number of drug trials. On the plus side, they enabled us to use the drugs on public sector patients, which we had never been able to do. We treated several hundred patients. It was great for our patients to have the disease turned around instead of going downhill all the time. There was also money that came in, which was good for research. And also some money came into our hands as well. It was seemingly on that sort of level, win/win. Win for the patients, win for us, and win for research. Everybody was happy.

Some doctors, stepping away from hands-on practice, ironically became more successful clinicians, more helpful to those in desperate need of treatment, by becoming investigators. As one doctor in Soweto’s Chris Hani Hospital put it, “We became more researchers than treaters; so we were in a better position, because we could get children into clinical trials.” Those trials stood as a welcome contrast to the lugubrious grind of AIDS care. As one physician working in Cape Town remembered:

It was a wonderful sort of revolutionary place because you know your patients could come there and get better. That was the exciting thing. All those years at the PM clinic, which stood for “afternoon clinic” because it was used for the HIV clinic (until somebody pointed out it could be “post-mortem”), we were following up people’s CD4s that were just going down the tube. But wherever we could, we tried to enter our patients into clinical drug trials. So I had the pleasure of watching a whole cadre of special patients that I loved actually blooming on drug trials.

Some people with HIV learned that anti-retroviral therapy could mean the difference between life and death. They began to question the manner in which research subjects were identified and asserted that equity required that they be included among those who would have a chance. A doctor in Soweto recalled:

A woman came to me and said, “How come if you are white and gay and live in Johannesburg you can get into a treatment trial; how come you don’t get us into these treatment trials?” So in 1996, we started approaching drug companies, and at first no one would touch us because these were Black women. They were illiterates. They lived in shacks. They were not going to take their medicine. They were going to fall out of studies. So nobody would give to us. Luckily, there was a woman who was the medical director of Pharmacy Upjohn in South Africa who was at medical school with us and decided to cut us some slack, and said I will give you one study. In three months, we were the second highest in enrollment in the world, and our results were good. Women, if they are supported, they are going to take their medicines.

But however inclusive, by its very definition research must exclude. Some will be drawn from the pool, others will be left to the downward spiral of HIV disease. Under such circumstances, where making a selection is, in effect, “playing God,” how are patients to be chosen? Even when pharmaceutical companies developed the criteria, there were more candidates than slots. One physician in Durban described the selection process for a trial with 30 participants. In this instance, the rationing principle was first come, first served:

There was a very careful interview process to explain what the study was, and the study was CD4 counts and viral loads; so that was taken into account. That was hard, because there are always more people that would love to be in the trials than there are spaces. It was very much the first people who were accepted who were in the trial; and when the numbers were closed, then that was as far as it went.

In addition to clinical criteria, a litany of limiting factors might define eligibility. In Khayelitsha, a township outside Cape Town, the Médecins sans frontières (MSF) clinics that sought to provide anti-retrovirals under the rubric of “operational research” (thereby eluding the government’s strictures on ARV treatment in the public sector) relied on committees to undertake the task of selection. In a neighboring community, Guguletu, in another operational research project, a team of health workers weighed a hefty set of selection criteria before doing “the Solomon thing”:

People have to have a CD4 count of under 400 or an AIDS-defining illness. They have to live within Guguletu, Nyanga district. They have to be attending one of the clinics in the district for at least 6 months. They have to disclose to at least one person in the community. They obviously have to be willing to take part in our program, which means attending all our meetings. And they have to be willing to have a therapeutic counselor. They also have to be mobile and able to get to the clinic themselves.

Despite these extensive criteria of judgment -- attempts to reduce the burden of “playing God” by making the act of selection both impersonal and objective -- the force of an individual personality, of all-too-human emotion, could break through the constraints erected against impulse and favoritism:

I had a young woman who had quite severe pulmonary disease with pulmonary hypertension. She was quite breathless, and the question was, is this the reason to give her drug to somebody else who will live longer, because she has another illness which may kill her before the HIV does? So we had agreed on every other front; she was treatment ready; she was psychologically sound; she filled all the other criteria. But what about her physical state? And she must have gotten wind that she was hanging in the balance. As I walked into the clinic, she did some star jumps and jumped up and down and moved her arms, and she said, “See doc, I am fine; I am absolutely fine.” There was just no way that I could actually say she mustn’t get the drug. I mean, there are just times when somebody’s needs and psychology, and the fact that they are human beings, just overwhelms every sense of better judgment. I didn’t even examine her. I walked straight out and said she has to go onto treatment. I can’t refuse.

But it was also necessary to determine, within the limits of resources, how severity of need should affect the prospect of being selected. The instinct to rely on the rationing principle -- give first to those in greatest need -- had to confront the claims of institutional survival:

We had to make sure that they are not too sick. Too sick patients have a very high mortality, and that is tough on the program. It feeds the propaganda that drugs are toxic. It's very time consuming for primary health care clinic expertise. It's tough on resources.

For all the joy of seeing patients flourish once on ARVs, either through clinical trials or "operational research," doctors were reminded of those who had been excluded. In a society where the Government refused to offer anti-retrovirals to those who might benefit, the consequences were dire:

I appreciate the Minister of Health's talk, sort of saying, "Bear with us, we need partnerships; we are doing what we can." The all-pervading thought going through my mind is, I just think of all the people, and I knew many of them, where we just watch them get more ill and eventually die, and have nothing to offer them other than, I think, pretty good opportunistic infection care. And at least we can offer them that; but having by default to visit people in their homes and organize palliative care, when you could see other people getting better and doing well, I think the inequality and injustice of it is particularly a horror.

In both Khayelitsha and Guguletu, the research programmes were designed with no endpoint. Treatment would continue indefinitely, as long as resources held out. But that was not typically the case in clinical trials, which, by definition, would conclude once the efficacy of a given drug had been assessed. In South Africa, where clinical trials were the only source of ARVs for many in the public sector, it was inevitable that the question of what would happen to research subjects when the trial ended began to surface. Did the principle of justice necessitate the provision of effective treatment indefinitely? Was it the moral obligation of the pharmaceutical firm to shoulder such costs? What duty did researchers have? Should they press for continued and unlimited access to effective pharmaceuticals beyond the trial's end? Given these concerns, some ethics committees refused to approve trials in which subjects would not be guaranteed post-study access to effective drugs:

The first time we submitted this trial to the ethics committee, they turned it down because they said the company promised to give us 2 years afterwards and that wasn't enough. They wanted life-long. We told the women in our support group, and the women said, "No, we want to meet this ethics committee." And those women sat there and said, "I'm HIV infected and I am dying. I can be on this trial for 2 years, and if I do well, I've got another 2 years access; it's 4 years, and you are turning this down, so you are killing me." There was this ethics committee of white, middle aged men who looked at these women and for the first time were confronted with these kinds of issues. And in fact, they then approved the study.

Moved by the desperation of their patients, clinicians who took their fiduciary responsibilities seriously also felt a distinct ethical queasiness.

Of course, the real ethical issues are what do you do at the end of the study, and what do you do for people who are failing therapy. If you are failing therapy in the States, you would go onto alternative therapy that may work. Here there was no alternative. Some of the trials, at the end of the trial, therapy was finished. Others would say, if you have treatment success you can continue. They would define success very strictly. So somebody is clinically benefiting, gaining weight, looking great, but they aren't under 50 copies per milliliter; they had to quit at the end of the study. That put us in a very difficult position ethically. Very, very difficult position. It didn't feel clean.

The struggle over post-trial access was embedded in a larger political context. President Thabo Mbeki had, by the end of the 1990s, begun what seemed to every doctor we interviewed

an utterly inexplicable romance with the discredited Peter Duesberg, the American scientist who rejected the thesis that HIV caused AIDS. Those who accepted his perspective viewed anti-retrovirals as dangerously toxic. Physicians who promoted their use were suspected of being agents of the pharmaceutical industry, forsaking their loyalty to nation and people.

Indeed as clinicians pressed to widen access to ARVs – only universal access could obviate the need for rationing—in alliance with the grassroots Treatment Action Campaign, the Government responded with fury. Those who had provided anti-retrovirals were denounced in a broadside, *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics*, some have traced to the office of the President. It declared, “We do not know how many of our people have died, as those at Chris Hani Baragwarnath Hospital conducted experiments on our people or ‘treated’ them relying on dangerous results of clinical trials.” Referring to a clinical researcher who had openly challenged government’s position, the document went on:

“[Who] must be held accountable how has this been exposed?”
Since Chris Hani Baragwarnath Hospital must be held accountable how has this been expressed?

“We must ...know that we have succeeded to produce geese among us that have been fattened by those who hold us in contempt.

Those appalled by the toll of disease increasingly came to believe that the failure of the government to act, to broaden treatment access, even if universal access would take years to achieve, represented a grave moral and political error. The consequence was avoidable suffering, preventable death. It was Government that was imposing conditions that made rationing, rationing by clinical trial, operational research, or ability to pay the dominant rule of treatment access. The Government’s failure was all the more inexplicable, given the legacy of apartheid and the struggle to overcome the years of racist rule.

A physician working at Chris Hani Hospital thus declared:

This is the antithesis of everything that the struggle was about. We were fighting for democracy, for people’s rights. We were allowing our own government, a democratic government, to basically allow 50,000 babies die each year. And so it went to the core of my whole philosophy of life. I think history will view the actions of this government as regards HIV/AIDS very seriously. I am still a supporter of the ANC, but this is genocide.

A colleague at Chris Hani Hospital drew the only possible conclusion, given the invocation of genocide:

They are going to have to go on trial. They are guilty of genocide. They are guilty of human rights atrocities from Mbeki down to the Department of Health... We are looking at people dying, and we can intervene, and all that is happening is obstruction, left, right and centre.

For black doctors who felt similar outrage it was not as easy to invoke the language of trials and genocide against the ANC that had led the struggle against apartheid. One physician who had been trained as a doctor under the sponsorship of the ANC, and who had lived in exile,

said that the ANC “was like a home.” There was no possibility of struggling for change in AIDS policy with a political formation outside the party.

In August 2003, under intense pressure, the Government announced that the Cabinet had approved a plan to roll out anti-retrovirals treatment over a period of five years. Seventy-seven sites were to be selected throughout the nation to implement treatment in the first year. A commitment to geographical equity dictated that at least one site exist in each of the nation’s health districts. The long awaited roll out will not, however, put an end to rationing. Although the plan assumed that 400,000 individuals would develop AIDS-defining illnesses in 2004, only 53,000 would be placed on treatment in 2003/04. In the program’s 2nd year, the cumulative number of treated cases would rise to 188,000. Only by 2008/9 would the program reach its target of just under 1.5 million treated cases. In the interim those not covered by the ever expanding treatment network will get sick; untold numbers will die. For the untreated, their families and the communities from which they come, the promise of universal care and the end to the rationing life will seem a very distant promise, one that, if reached, may simply be too late. Time in the interregnum will have served as the ultimate standard of rationing. In the words of one of our doctors, heading a rural hospital not selected for the roll out, at least not yet,

It feels strange to see the new possibilities so close... And yet, so far to go.

