

RE-EXAMINING THE EARLY YEARS OF ANTI-RETROVIRAL TREATMENT IN SOUTH AFRICA: A TASTE FOR MEDICINE

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ABSTRACT

Antiretroviral treatment (ART) has become a ubiquitous feature of South African life. By early 2015, three million people had begun ART in South Africa. In light of widespread positive responses to the availability of treatment, early ethnographies that stressed suspicion, fear and resentment need to be revisited. In this article, I re-examine my own data on an early encounter between the technologies of ART and the population of a rural district in the Eastern Cape province. I also return to Didier Fassin's ethnography in which he placed ordinary people's responses to AIDS in a history of suspicion and resentment. The article focuses in particular on the support groups that ART users formed and argues that they were the sites of creative responses to ART in which ordinary people, primarily women, bent the new technologies and esoteric languages they encountered to an array of endogenous purposes. The article concludes that ART was incorporated into a politics of hopeful expectation rather than a politics of resentment.

THREE MILLION PEOPLE HAD BEGUN ANTIRETROVIRAL TREATMENT (ART) in South Africa by 2015,¹ rendering it among the most extensive medical interventions in recent times. The effects measured in basic demographic data have been dramatic. In the decade from 2005, when the ART rollout began in earnest, South Africa's mortality rate fell by 25 percent. Life expectancy at birth climbed from 52 years to 61 years.² The programme has by no means been an unmitigated success. Coverage remains woefully low in parts of the country, while in others, perennial stock-outs have left people without their medicines for extended periods. What can be said with confidence is that large numbers of people have responded positively to the availability of treatment.

The purpose of this article is to go back to the beginning, as it were, and to re-examine some of the first encounters between this new technology and ordinary people. To what sorts of social and political uses did those who first encountered ART put it? What were some of the

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¹ Nhlanhla Nene, 'Budget Speech, 2015,' South African Treasury Home Page available at <http://www.treasury.gov.za/documents/national%20budget/2015/speech/speech.pdf> (15 July 2015).

² Statistics South Africa, 'Mid-year Population Report', (Report, Pretoria, 2014), p. 6.

ways in which they spoke about it? Above all, why did many people respond with enthusiasm to the availability of ART?

An exploration of this grassroots enthusiasm is interesting for several reasons, not least because many AIDS activists and ethnographers did not anticipate it. In 2005, for instance, a year after the South African government finally began rolling out ART across the public health system, Edwin Cameron, a South African judge and one of the country's leading AIDS activists, issued a dark warning. In 2001, Cameron wrote, the government of Botswana, knowing that about 100,000 of its citizens would soon die if not treated soon, announced that it would provide free ART to everyone who needed it. By the end of 2003, two years after the launch of the programme, 15,000 people were on treatment. The rest – more than 85,000 – had stayed at home and were either dead or dying.³

Cameron clearly worried that the same fate lay in store for South Africa. The country's treatment movement had just won a long and wounding battle to have the government commit to providing universal ART coverage.⁴ This victory would prove tragically Pyrrhic if people with AIDS were to stay at home and die. Cameron argued, controversially, that those too ashamed to get treatment had lost sight of their own interests and that their fate ought to be nudged out of their hands.

The news ethnographers were bringing in from the field was hardly encouraging. Here I include my work. In 2005, I began a study of a Medicins Sans Frontieres ART pilot project in a rural district of the Eastern Cape province. I ended up writing a book about a young man's two-year battle to decide whether to test for HIV.⁵ Although he was convinced that he was HIV-positive, and despite the obvious efficacy of the treatment he witnessed, he did not test. My book thus suggested that however well ART was administered, the political, social and emotional obstacles to people coming to get it were immense.

I was not alone. Didier Fassin's 2007 book, *When Bodies Remember*, arguably still the most authoritative ethnographic monograph on South Africa's AIDS epidemic, warned that in their response to AIDS, ordinary South Africans took part in an "economy of resentment ... and an economy of suspicion".⁶ Their resentment was of a long colonial past during which public health expertise had been used to subjugate them. And their suspicion was that those who hold power, including the power to use science and produce new technologies, had an interest in concealing the causes of illness.

In hindsight, with three million people on ART in South Africa, this early ethnographic work is in need of revision. It is not that either Fassin or I were wrong. The fears of the young man I studied were real enough, as were the resentment and suspicion Fassin reported. But

³ Edwin Cameron, *Witness to AIDS* (Cape Town, Tafelberg, 2005), pp. ii-iv.

⁴ For an account of this battle, see Nicoli Nattrass, *Mortal combat: AIDS denialism and the struggle for antiretrovirals in South Africa* (University of KwaZulu-Natal Press, Pietermaritzburg, 2007).

⁵ Jonny Steinberg, *Three-letter plague: A young man's journey through a great epidemic* (Vintage, London, 2009).

⁶ Didier Fassin, *When bodies remember. Experiences and politics of AIDS in South Africa* (University of California Press, Berkeley, 2007), pp. 170-171.

there was clearly much else going on: feelings, languages and emerging practices that both Fassin and I observed, but which we did not give sufficient analytical due.

The aim of what follows is twofold. First, I return to some of the data I gathered in the mid-2000s, as well as to some subsequent ethnographic work on AIDS treatment. I spent many hours in ART support groups and talking individually to people on ART. While much of this data is in the book I wrote, it is overshadowed by the book's central subject, which is fear and reluctance. My purpose here is to give the forums that emerged around ART analytical attention in order to ask, simply, what those who embraced ART did with it.

My second aim is to re-examine Fassin's argument. The force of his book lies not just in its meticulous ethnographic work, but also in its conceptual scale. It places the responses of ordinary people to medicine in an intricate and powerful account of medical and imperial history. I rehearse why he took resentment and suspicion to be the predominant response of ordinary people and why this argument requires revision.

Fassin's Mbeki and the resentment and suspicion of ordinary people

It is best to begin with a very brief political history of the early years of AIDS treatment in South Africa. There is no uncontroversial telling of this history. What follows here is as schematic and as simple as possible.

When a successful course of treatment for AIDS was pioneered in Vancouver, Canada in 1996,⁷ an urgent question arose: could ART be made widely available in the region most afflicted by the epidemic, sub-Saharan Africa? From the price of the drugs, to the capacity of health systems to deliver them, to the willingness of people to take them, a host of obstacles presented themselves. In South Africa, in 1998, a number of former anti-apartheid activists and others formed the Treatment Action Campaign (TAC), its primary purpose to use a combination of legal action and mass mobilization to force the pharmaceutical industry to lift patents on antiretroviral medicines, making them affordable in the developing world.⁸ The TAC successfully sought an alliance with South Africa's first democratically elected government. A victorious, jointly litigated court action saw global patents on antiretroviral medicines lifted. In 2001, Indian pharmaceutical companies began manufacturing generic antiretroviral drugs at a fraction of their patented price.⁹

⁷ It was successful in the sense that the treatment halted the replication of the virus while people remained on it.

⁸ Much has been written on the TAC. I have found the following to be among the most informative and incisive: Nathan Geffen, *Debunking illusions: The inside story of the Treatment Action Campaign* (Jacana, Johannesburg, 2010); Mandisa Mbali, *South African AIDS activism and global health politics* (Palgrave, London, 2013); Steven Robins, "Long live Zackie, long live": AIDS activism, science and citizenship after apartheid', *Journal of Southern African Studies* 30, 3 (2004), pp. 651-672.

⁹ Geffen, *Debunking illusions*, pp. 14-23.

This turned out to be the high-water mark of the alliance between the treatment movement and the South African government.¹⁰ At much the same time as the historic court victory over patents was being celebrated, South Africa's president Thabo Mbeki, under the influence of the online literature of a largely American-based, dissident movement, began publically to question whether HIV was the primary cause of AIDS. He asked, too, whether ART did not hasten the deaths of AIDS sufferers due to its toxicity.¹¹ His Health Minister Manto Tshabalala-Msimang soon fell under his sway.

South African government policy on AIDS quickly became entangled in contradictory imperatives. On paper, the government committed itself to a universal rollout of prevention of mother-to-child treatment and spoke of committing itself to providing treatment for everyone with AIDS. In practice, health officials received mixed messages from above, and both programmes stalled. The TAC turned its attention to challenging the South African government and won a major victory in 2002 when the South African Constitutional Court ordered the government to roll out its prevention of mother-to-child transmission treatment programme. In 2004, the South African cabinet turned against Mbeki on the matter of treatment and authorized the universal rollout of ART.¹²

The politics of the controversy were painful and difficult. While it is clear that there was a great deal of unease about Mbeki's position both in the ruling African National Congress (ANC) and in the health department, criticism of Mbeki from within the ranks of the country's former liberation movement was muted. Indeed, the politics of the battle were saturated with powerful, if often ineffable, racial meanings. Precious few of the South Africans who rallied behind Mbeki were white. Although a handful of his detractors were not, being black and opposing Mbeki, at least in public, appeared to be to concede too much. Behind him was an alliance cemented by racial solidarity.

It is in this context that Fassin's ethnography is best understood. Although published in 2007, much of the fieldwork that went into when *When Bodies Remember* was conducted in the early 2000s, and the politics of that moment animates Fassin's book. Methodologically bold, the book endeavours not just to conduct parallel ethnographies of the high politics of AIDS and the experiences of ordinary people suffering illness, but also to show deep connections between the two. More specifically, Fassin wanted to show that Mbeki's AIDS heterodoxy, far from being eccentric or unintelligible, reflected deep and widespread experience among black South Africans.

Mainstream Western opinion could not comprehend Mbeki's position. It was widely believed that insofar as his views were sincerely held, he was mad.¹³ Others assumed that his

¹⁰ The relationship had in fact been riddled with tensions from the start. See for instance, Fassin, *When bodies remember*, pp. 41-54; Helen Schneider and Jo Stein, 'Implementing AIDS policy in post-apartheid South Africa', *Social Science & Medicine* 52, 5 (2001), pp. 723-731.

¹¹ Mark Gevisser, *Thabo Mbeki: The dream deferred* (Jonathan Ball, Johannesburg, 2007), chapter 41.

¹² Anthony Butler, 'South Africa's HIV/AIDS policy, 1994-2004: How can it be explained?' *African Affairs* 104, 417 (2005), pp. 591-614.

¹³ Jeffrey Herbst, 'Mbeki's South Africa', *Foreign Affairs* 84, 6 (2005), pp. 93-105; RW Johnson, 'The native paranoia of Thabo Mbeki', *Wall Street Journal*, 7 December 2007, p. A24.

views could not possibly be sincere. Explanations for his position thus took the form of disquisitions on his hidden motives. Some said he had calculated that treating the ill would bankrupt his country while allowing them to die would not. Others suggested that his AIDS heterodoxy was a ploy to maintain his controversial centre-right economic policies while keeping the loyalties of the South African left. Loudly attacking an alliance of big pharma, white racism and the scientific establishment would mask his own conservatism.¹⁴

Fassin took a radically different stance. He argued that the incomprehension of Mbeki was a form of social ignorance and that if we understood the sources of Mbeki's views we would learn a great deal about the aetiology of South Africa's AIDS epidemic and about power and inequality more broadly.

Fassin's central contention is that there is an intimate connection between Mbeki's views on AIDS and ordinary people's experiences of the illness. Mbeki's heterodoxy ought not to be characterized as denialism, Fassin argues, but as a species of knowledge about domination and its history. It is a knowledge shared by ordinary people who understand AIDS as the latest episode in a long history of suffering inflicted by others, and who greet the scientific establishment's diagnosis of their ills with mistrust. What both Mbeki and many AIDS sufferers partake in, Fassin argues, is 'an economy of resentment' and 'an economy of suspicion'. The former 'typifies the painful relationship that dominated people have to their history',¹⁵ while the latter is characterized by 'the notion that something essential is being kept from us about the truth of the world and that it is in the interests of those who hold the reins of power to hide it from us'.¹⁶ These economies paralyze action, for 'dominated people ... are caught up in a powerlessness that they justify by their history'.¹⁷ Embodied in Mbeki's heterodoxy then, was generations of bitter knowledge shared by millions of South Africans, who felt that the discourses and practices of public health had for a long time been used by the powerful to condemn and shunt around the weak and that the roots of the illnesses wrought by white domination in Africa had so often mistakenly been placed by medical science in Africans themselves.

Fassin's argument about the connection between Mbeki's politics and the experiences of ordinary people is a subtle one. He is not arguing that the majority of black South Africans adopted Mbeki's scepticism about the connection between HIV and AIDS. But he is suggesting that the political sensibilities that Mbeki's heterodoxy exuded were understood by masses of people as their own. Mbeki managed to rally the majority behind him in 'a coalition of shared memory and identity'.¹⁸

¹⁴ Peter Beinart, 'Social disease', *The New Republic* 21 January 2002, pp. 14-16.

¹⁵ Fassin, *When bodies remember*, p. 170.

¹⁶ *Ibid.*, p. 171.

¹⁷ *Ibid.*, pp. 170-171.

¹⁸ *Ibid.*, p. 120. Although Fassin does claim, without reference, that as late as 2005, polls showed widespread support for the Mbeki government's position on AIDS among black South Africans. Didier Fassin, 'The case for critical ethnography: Rethinking the early years of the AIDS epidemic in South Africa', *Social Science & Medicine* 99 (2013), p. 123.

Re-examining the early years of ART afresh

These connections between Mbeki's heterodoxy and ordinary experience need to be examined afresh. It is not just that the coalition behind Mbeki melted in a short time and that African nationalists of all stripes have embraced orthodox views on AIDS and its treatment without embarrassment. Of greater interest is that the provision of ART has become the occasion for a new quotidian relationship between state and people that is both intimate and pervasive. In hindsight, it is safe to say that back in the mid 2000s, when ART was first being rolled out at scale and ordinary South Africans were confronting it for the first time, something other than suspicion and resentment was in play. In what follows, I return to those times by re-examining my old fieldwork experience as well as the fieldwork of others (including Fassin's) in an attempt to reconstruct aspects of the encounter between AIDS medicine and ordinary people.

From October 2005 to November 2007, I conducted an ethnographic study of a treatment programme jointly run by *Médecins Sans Frontières* (MSF) and the Eastern Cape Department of Health in a rural town called Lusikisiki. The population of the town and its outlying villages numbered 150,000. Poverty was widespread; a census conducted in a Lusikisiki village in the mid-2000s found that a third of households relied primarily on state grants for income.¹⁹ HIV prevalence was very high; 31 percent of women presenting at antenatal clinics were testing positive when the programme began in 2003. The district was served by 11 public healthcare clinics and a hospital. MSF's task was to have these public institutions provide full ART coverage to the district's population.²⁰

The stakes for MSF were extremely high. The programme had begun in 2003 in the midst of the national controversy about AIDS and its treatment. Although ART had proved successful in pockets of urban South Africa, it had yet to be attempted at scale anywhere in the countryside. Would rural South Africa's notoriously rickety healthcare system prove capable of delivering it? Would the rural population come and get it? MSF regarded this pilot as make or break; if it failed, they would be gifting ART's detractors a handy argument.²¹

By the time I arrived in 2005, Mbeki's cabinet had overruled him and the government was committed in principle to a national rollout, but the political environment was hardly hospitable. Mbeki remained president and Tshabala-Msimang health minister, all sort of contradictory messages were coming from above, and there was plenty of ill will about. My ethnographic work took two forms. I based myself in a small, outlying village that had just encountered the ART programme for the first time when I began work. I could thus record villagers' response to ART from its inception. The second leg of my research took place in

¹⁹ Flora Hadju, 'Relying on jobs instead of the environment? Patterns of local securities in rural Eastern Cape', *Social Dynamics* 31, 1 (2005), pp 239-254.

²⁰ Martha Bedelu, Nathan Ford, Katherine Hilderbrand and Hermann Reuter, 'Implementing antiretroviral therapies in rural communities: The Lusikisiki model of the HIV/AIDS healthcare', *Journal of Infectious Diseases* 196, 3 (2007), pp. S464-S468.

²¹ Among MSF's tasks was to show that nurse-led primary health care clinics, and not hospitals, were the most appropriate institutions to administer ART. This was extremely controversial at the time; unfortunately I do not have the space to outline the terms of the debate here.

the institutions of the ART programme itself: in the clinics and the hospitals, among nurses and doctors, the young volunteers who ran ART support groups, the TAC branch that had just been established in town.

The suspicion and resentment of which Fassin speaks was very much in evidence right from the start of the initiative. The white MSF doctor who spearheaded the programme introduced himself to the local population by travelling from village to village personally conducting voluntary HIV tests. Within weeks, rumours circulated that the doctor was spreading HIV in his needle. It was said that he was an agent of the old apartheid regime; that a conspiracy was in progress to infect so many black people with AIDS that whites would become an electoral majority. In one village, a hostile crowd confronted the doctor with this accusation. The tension only abated when he stood up on a table, drew his own blood in front of the assembled crowd and explained as best he could the science behind the tests that would be done on it.

The historical resonances of this moment were powerful. Nearly eight decades earlier, in 1918, in the wake of the great flu epidemic, the South African authorities distributed flu inoculation kits to the very villages in which the MSF doctor was now working. The public health officials distributing the kits were preceded by ‘whispers that the “long needle of the White man” [had come] to inject more harm’, the historian Benedict Carton writes.²² ‘Xhosa-speaking messengers kept one step ahead of vaccination efforts, warning of “a device of the Europeans to finish off the Native races of South Africa”’.²³

I found no memory of the 1918 incident during my time in the villages of Lusikisiki. But the original suspicion – that disease-control measures were instruments of white domination – remained. I found, too, an urgent quest among some people, especially young men, to find an indigenous cure to AIDS. It was not just that people wanted to believe that Africans had sufficient reservoirs of knowledge and expertise to tame death. They wanted also to short-circuit the doctors and nurses and the biomedical knowledge they felt they had reason not to trust.

While suspicion may have been the most vocal of the early responses to the arrival of ART, it was hardly the only one. A quieter, but no less dramatic response, one embarked upon in disproportionate numbers by young women, was to test for HIV. Quite how dramatic was illustrated on the Saturday morning in the summer of 2005 when ART arrived abruptly in “Ithanga”, the name I have given the village in which I was based. In the preceding weeks, lay counsellors had met with the local chief to obtain his permission to perform Voluntary Counselling and Testing (VCT) in the village and had then gone from door to door to inform residents of their plans. Now, early on the Saturday morning, a group of nurses and lay counsellors set up a mobile VCT centre at the local school.

²² Benedict Carton, ‘The forgotten compass of death: Apocalypse then and now in the social history of South Africa’, *Journal of Social History* 37, 1 (2003), pp-119-218, p. 204.

²³ *Ibid*, p. 204.

During the course of testing day, a great many of the village's 700 or so inhabitants drifted to and from the school. Most had come not to test but to watch. Their curiosity was profoundly ungenerous: they had come to see who was HIV-positive. It was, they believed, not hard to tell. As one informant explained:

To know who was positive and who was negative, you just had see for how long the people stay. There is counselling before the test, and counselling after the test. The counselling before the test, it's the same for everybody: a few minutes. But the counselling after the test: for some it lasts two minutes, for others, it is a long, long, time. They don't come out for maybe half an hour, even an hour. Then you know that they are positive.

On that Saturday morning in February 2005, 39 people went to the school to test for HIV, the majority of them young women. By the end of the day, according to several informants, the village had identified nine or ten of them as HIV-positive.²⁴

What followed was a long period of watching. Young women who fell ill and sought ART were guinea pigs, their physical health the subject of close scrutiny and whispered observation. The empirical evidence was not always easily legible. Women would go onto treatment and become more ill. Rumours circulated that women from other villages had begun treatment and died.

Over time, the signs of biomedicine's efficacy proved very powerful indeed. The evidence seldom took the dramatic form of the so-called "Lazarus effect" – those at death's door suddenly arising and walking back into the world. It was subtler than that. Above all, the work medicine did on women's bodies demonstrated its capacity to delineate the boundaries of the epidemic, as it were, to show where AIDS ended and other medical problems began. As one informant put it:

We started noticing things we had not noticed before. For example, the people who were saying that the marks on their skin were the work of *ichanti* [a demonic snake] went to the *inyangas* [herbalists] to be treated against witchcraft and many got sicker and died. The people with the marks on their skin who went to the clinic were told they had shingles and that it was because of Aids. They were given drugs for their skin and they got better.

Similarly, people displaying the symptoms of neurological disorders, long associated with witchcraft, were diagnosed as having AIDS dementia and cryptococcal meningitis and were treated with drugs.

And so an important early experience of ART and its associated technologies took the form of a type of public theatre: an audience watched the work biomedicine did on women's bodies. It was neither a benign audience nor a pleasant theatre. Observations of women's health was often cruel and mingled with talk of their sex lives and their morality. 'Some said that ARVs are the medicines of the *isifebe* [loose women, sluts]', one informant told me. That

²⁴ MSF records show that ten people tested positive in Ithanga that morning, and so rumour and gossip proved accurate in this instance.

it was predominantly women who sought treatment and who thus offered themselves, as it were, as evidence, was in keeping with ART just about everywhere else in the country. As many as 70 percent of those who began treatment in South Africa in the mid-2000s were women.²⁵

There are several reasons for this, some more complicated than others.²⁶ One is that the African AIDS epidemic is more prevalent among women than among men; in southern Africa in the mid-2000s, women accounted for 59 percent of the HIV-positive.²⁷ Another is that South African women, along with women elsewhere,²⁸ are considerably more likely than men to opt for medical treatment, whatever their ailment. A study based on data gathered in the late 1990s, for instance, found that South African men were 25 percent less likely than women to have visited a public sector clinic in the previous month.²⁹ The response of men to ART conforms to this pattern. At the time that ART arrived in Lusikisiki, the Actuarial Society of South Africa had estimated that 43 percent of those in need of treatment in South Africa were men, and yet men accounted for just 30 percent of those who were on it.³⁰ Even then, men who did seek treatment were far more likely than women to do so only once they were very ill.³¹

Therefore, one response to the arrival of ART in Lusikisiki was to voice deep suspicion, but another was to seek treatment. It is of course quite possible for one person to have both responses, and one should not create the impression of a Manichean divide between the sexes. Nonetheless, both of these responses were highly gendered. The young man about whom I wrote was seized with the idea that the MSF doctor carried HIV in his needle.³² While quantitative work on this question was not done in Lusikisiki, data from a range of sources would suggest that his was a familiar male response. In South Africa and the United States, serial studies have shown that those who suspect that HIV was concocted in a laboratory, or was deliberately spread among black people by medical technology, or has secretly been cured but the cure kept locked away, are overwhelmingly men.³³

²⁵ Helen Schneider, Veloshnee Govender, Bronwyn Harris, Susan Cleary and Mosa Moshabela, 'Gender differences in experiences of ART services in South Africa: A mixed method study', *Tropical Medicine and International Health* 17, 7 (2012), pp. 820-826.

²⁶ Josephine Birungi and Edward Mills, 'Can we increase male involvement in AIDS treatment?', *The Lancet* 376 (2010), p. 1302; Morna Cornell, James McIntyre and Landon Myer, 'Men and antiretroviral therapy in Africa: Our blind spot', *Tropical Medicine & International Health* 16 (2011), pp. 828-829.

²⁷ According to UNAIDS, [title of page](http://data.unaids.org/pub/GlobalReport/2006/Annex2_Data_en.xls), http://data.unaids.org/pub/GlobalReport/2006/Annex2_Data_en.xls (date accessed).

²⁸ See for instance, Will Courtenay, 'Constructions of masculinity and their Influence on men's wellbeing: A theory of gender and health', *Social Science & Medicine* 50, 10 (2000), pp. 1385-1401.

²⁹ Nicoli Nattrass, 'Gender and access to Antiretroviral Treatment in South Africa', *Feminist Economics* 14, 4 (2008), pp. 19-36.

³⁰ Ibid, p. 25.

³¹ Schneider *et al*, 'Gender differences', p. 821.

³² Steinberg, *Three-letter plague*, pp. 166-185.

³³ Laura Bogart, Glenn Wagner, Frank Galvan, and Denedria Banks, 'Conspiracy beliefs about HIV are related to Antiretroviral Treatment nonadherence among African American men with HIV', *Journal of Acquired Immune Deficiency Syndrome* 55, 3 (2010), pp. 648-655; Laura Bogart and Sheryl Thorborn, 'Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans?', *Journal of Acquired Immune Deficiency Syndrome* 38, 2 (2005), pp. 213-218; Clara Rubincam, *Alternative beliefs about HIV/AIDS: Re-*

I cannot prove it, but a case can be made that one response – seeking treatment – acted upon the other – voicing suspicion. Talk that the doctor carried HIV in his needle, so threatening in the early days of the programme, did not last; it seemed to fly in the face of the evidence. And if the evidence did indeed mute suspicion, it also encouraged doubters to seek treatment. After a slow start, the numbers of people beginning treatment gathered pace. By the end of 2006, 2,200 people had begun ART in Lusikisiki.³⁴

Support groups as feminized public fora

As described above, those who began treatment may have provided evidence for the efficacy of biomedicine, but only by virtue of being watched and judged, often unkindly. But ART also offered the opportunity for at least some of those on treatment to act. It created new institutions that gave people occasion to assemble where they might command the new technologies of AIDS treatment and bend them to new purposes. These institutions were the support groups that formed around the 11 clinics that administered ART.

Weekly attendance at support groups was compulsory in the lead-up to initiation of treatment, and everyone on ART thus got at least a taste of them. I periodically attended two of the 11 weekly Lusikisiki support group meetings for the duration of my research. In the end, I sat in on about 25 such meetings, and I conducted individual interviews about these meetings with fourteen support group members.

From the first meeting I attended in early 2006, it was apparent that a powerful hierarchy was at work, and those at the top were not just women, but almost invariably young women. There was a handful of men at the meeting, some of them young, one or two middle aged; to a man, they all spent the meeting in silence. It is difficult to stress the unusualness of such a scene in a place like Lusikisiki. The only other organizational forms I knew of where women wielded such power was in women's-only church societies, and these were usually middle-aged matriarchs.

Each support group meeting was run by a person called an adherence counsellor. In some cases he, but in most cases she, had been trained by, and earned a salary from, MSF. She was thus, in a way, the doctor's proxy, or at any rate the one who stood in for his biomedical knowledge and thus his authority. The next tier in the hierarchy was occupied by people who had been on ARVs for some time and were confident to talk about AIDS medicine; most were young women. Perhaps the most distinctive thing about them, aside from their age and their gender, was the combination of esoteric languages they used. Some of it was biomedical. The names of a host of drugs spilled easily from their tongues. They knew off the tops of their heads which combinations of which medicines treated which side effects, which antiretrovirals should not be combined with which antibiotics, at what stage a patient should move from first-generation to second-generation treatment, and so forth. Some of the esoteric

examining distrust among young adults in Cape Town, South Africa, (London School of Economics, unpublished PhD dissertation, 2013).

³⁴ Interview, Dr Hermann Reuter, Lusikisiki, 5 March 2007.

language they used was both biomedical and at the same time something else. This something else is perhaps best called ‘conversion language’; people who begin attending support groups are told that they must change some of their ways if the drugs are to work.³⁵

The task of identifying conversion language is not straightforward, for it is always closely bound to, and is in fact parasitic upon, biomedical language. One needs to tease the two apart. For instance, at each support group meeting I attended, members were told that if they smoked, drank alcohol or took any traditional medicine while they were on antiretroviral drugs, they would die. They were not told that they should smoke in moderation, or that they ought not to get blind drunk, or that they should find out what was in a traditional medicine before taking it. They were told that if they did not abstain entirely from these three habits, their medicine would fail.

There is little medical basis for these assertions. Smoking may well kill a patient, but whether she is on ARVs is irrelevant to the damage tobacco might do to her. Drinking in moderation is perfectly compatible with antiretroviral medication. And yet, these assertions became sacred biomedical truths. Although MSF personnel recruited and trained the people who initially ran the support groups, they were mystified about the genesis of these assertions. ‘It comes from them, from the people on the ground’, the head of MSF South Africa told me. ‘And it is so stubborn, so firmly believed, that we have given up challenging it.’³⁶

At first I thought I had stumbled across a localized oddity confined to the clinics of Lusikiski. But over the course of my research I interviewed more than a dozen AIDS doctors working in an assortment of treatment programmes funded by a variety of donors; each, without fail, reported that lay-counsellors and nurses were warning patients that to mix ART with smoking or drinking was to create a toxic brew.³⁷ As other scholarly work on South African ART support groups began to be published, similarly findings were reported.³⁸ What, precisely, was at stake?

Prohibitions on smoking and drinking are not new in South African healing movements; they have been prevalent in various independent African churches for many decades.³⁹ During her fieldwork in the late 1960s and early 1970s, for instance, Jean Comaroff reported that the small Zionist congregations in the old homeland of Bophuthatswana, whose membership also consisted largely of young women, forbade smoking and drinking.⁴⁰

³⁵ See also Sakhumzi Mfecane, ‘Negotiating therapeutic citizenship and notions of masculinity in a South African village’, *African Journal of AIDS Research* 10, 2 (2011), pp. 129-138; Steven Robins, ‘From “rights” to “ritual”: AIDS activism in South Africa’, *American Anthropologist* 108, 2 (2006), pp. 312-326.

³⁶ Interview, Eric Goemaere, Cape Town, 21 July 2007.

³⁷ For instance, interviews with Dr Richard Cooke in Madwaleni in the Eastern Cape, Hoffie Conradie in the small town of Worcester in the Western Cape, and Dr Eve Mendel working in an AIDS programme in the townships of the southern Cape Peninsular, elicited similar findings.

³⁸ See especially, Mfecane, ‘Negotiating therapeutic citizenship’.

³⁹ Bengt Sundkler, *Bantu prophets in South Africa* (Oxford University Press, Oxford, 1964); Martin West, *Bishops and prophets in a black city* (David Phillip, Cape Town, 1975); Joel Cabrita, *Text and authority in the South African Nazareth church* (Cambridge University Press, Cambridge, 2014).

⁴⁰ Jean Comaroff, *Body of power, spirit of resistance: The culture and history of a South African people* (Chicago University Press, Chicago, 1985).

Comaroff understood these prohibitions as a ritual endeavour to tame an encroaching capitalist order. But in this instance it seems that the prohibitions function to work upon relations between women and men.

While it is true that men and women both smoke and drink, these activities play very different functions in their respective lives. Put simply, drinking, in particular, is constitutive of male sociability. It is one of the things men do together.⁴¹ To tell a man that he can never drink is to redefine himself in very uncomfortable ways vis a vis other men, to ask of him that he disrupt his sense of himself and the sense that other people make of him. A man who stops drinking with his peers will turn heads. People will ask him why. He will have to answer. The answer the support group wants him to give is that he has AIDS. It is a radical answer, one full of consequences.

Whatever the intentions or feelings of those who propagate the prohibitions, it seems that their effect is less to stop men on ART from smoking and drinking than to silence familiar male discourses in the support groups themselves and thus to seize control, as it were, of the uses to which talk of ART is put. One sees this especially vividly in the work of Sakhumzi Mfecane, who spent several years shadowing a number of HIV-positive men attending a support group in a rural Eastern Cape village, and who, like me, discovered that support groups warned gravely against the consumption of alcohol and tobacco. Mfecane reports two sorts of male behaviour in support groups. Some men say as little possible, their aim to keep under the radar. Others, by contrast, are very vocal. They adopt the dominant language of the group and present themselves as a version of men expected by the facilitators; they are, they say, men who do not smoke, who stay entirely away from drink, who strictly have just one sexual partner, and who always wear a condom.

Then Mfecane follows them around their lives outside of the support group. He discovers that as they walk away, so they shed the language they have spoken in the group. In the early evenings they join their friends in trading stores and shebeens, and they drink beer and smoke cigarettes. Some of them supplement their antiretrovirals with traditional medicines. In the main, Mfecane argues, they are using their antiretroviral treatment to approximate the sort of men they were before they fell ill, often in ways that celebrate the retrieval of their physical autonomy and their strength. These ways of living with AIDS are by their nature silent. Where AIDS treatment has a grassroots, public voice, it is overwhelmingly a feminized voice, even when the one speaking is a man.⁴²

Perhaps one of the primary functions of the prohibitions, then, is less to protect the health of people's bodies than to attend to the character of the support groups themselves. They become forums in which the relationships between men and women one encounters on the outside are suspended; space is thus made in which new practices might occur, new ways of speaking about the world take hold and new purposes emerge. What might some of these

⁴¹ Anne Mager, *Beer, sociability and masculinity in South Africa* (Indiana University Press, Bloomington, 2011).

⁴² Sakhumzi Mfecane, 'Narratives of HIV disclosure and masculinity in a South African village', *Culture, Health and Sexuality* 14, 10 (2012), pp. 109-121.

purposes be? There are no doubt many, and they surely vary a great deal across space and time, but several appear to be responses to some of the mysogeny that has typically accompanied talk on AIDS in South Africa.

We have known since Suzanne Leclerc-Madlala's ground breaking work in the late 1990s that women in South Africa have been widely demonized in the context of AIDS as dirty and lascivious.⁴³ Extensive research on women in antiretroviral support groups across South Africa suggests that an alarming proportion have been beaten by lovers, spouses and fathers, precisely because they have AIDS.⁴⁴ In fact, it is not uncommon that women in support groups have been thrown out of their homes by men and find support among a network of women, some of them extended family, some of them friends.⁴⁵

In the work of some ethnographers, it is clear that at least some support groups have become forums in which very different discourses about AIDS are tried out and nurtured. Philippe Denis, for instance, who conducted repeated interviews with ten members of an HIV-support group in Pietermaritzburg, found that more than a decade after she did her research, the demonization of women described by Leclerc-Madlala remained alive and well in the lives of his interviewees. This much had not changed. But what was new, he contends, was an assertiveness among women which he attributes to the time they had spent in support groups. The groups constituted a forum in which a new language about AIDS might evolve. ARVs figure prominently in the language of his respondents, not as objects of suspicion or as emblems of longstanding resentments, but as the corporeal expression of divine love. 'I took Christ as my personal Saviour,' one of Denis's respondents said. 'I took him as my Saviour in these ARV tablets, before I put them in my mouth. When I come from the clinic, I say, "Lord, there is nothing you can do better than these tablets"'.⁴⁶

There are much rawer and angrier feelings at work as well. It could be that with the prohibition on alcohol and other strictures, some women are saying that they now set the rules and that the rules will be severe on men: if you want the drugs that will save you, you will perform the tamed, neutered script we have written for you. By their nature, such motives do not easily present themselves for verification. But in my own work, I certainly caught a glimpse of them from time to time. In a group interview with four female adherence counsellors in Lusikisiki, for instance, I pressed my respondents about the prohibitions on alcohol and smoking. 'The doctors insist that there are no good medical reasons for them,' I said. 'It is not true that they make ARVs toxic.' 'Neither you nor the doctors understand our lives,' one of them snapped back. 'A man who has one drink will have ten. And so we say that if he wants to live, he must have none. The place of ARVs is our place, not theirs. A man who cannot obey our rules must go away and leave the pills for someone who deserves them.'

⁴³ Suzanne Leclerc-Madlala, *Demonising women in the era of AIDS: An analysis of the gendered construction of HIV/AIDS in KwaZuluNatal* (University of Natal, unpublished PhD dissertation, 1999).

⁴⁴ Schneider *et al*, 'Gender differences and experiences,' p. 822.

⁴⁵ Ibid, p. 823.

⁴⁶ Philippe Denis, 'New patterns of disclosure: How HIV support group members in KwaZulu-Natal speak of their status in oral narratives', *Medical History* 58, 2 (2014), p. 294..

I also witnessed in Lusikisiki support groups the occasional eruption of a freer and more playful kind of talk, its subject sexual desire. At a meeting of the support group in Lusikisiki town centre in September 2006, for instance, a debate was entertained. When sleeping with somebody new, is it incumbent upon one to declare one's HIV status? One young woman said yes, of course it was; another said no, of course not. A heated argument ensued, four or five young women insisting that to have sex with a new partner without disclosing was deeply irresponsible. Their opponents, also all young women, said no, what if you really desire this man, urgently, here and now; to tell him that you are HIV-positive is to chase him away.

Many observations might be made of this discussion. One is to note that there were several middle-aged men and women in the meeting and they seemed to have the power neither to intervene nor to get up and leave. It seemed to me a heady and excited moment in which young women tested the more provocative regions of the new discursive terrain they had made. For a moment, at least, they could enact the dissolution of gerontocratic hierarchies.

There is, perhaps, another purpose for these feminized spaces, one that is as important as it is difficult to pin down and describe. These forums are immensely exciting for at least some of their participants, I would contend, simply because they have made it possible for young women to participate in the existential achievements of public participation. To speak and to act in a forum constituted by one's equals; to be seen to build and mend and fortify the foundations on which this forum stands – this is to imbibe an ancient and powerful experience from which young women have since time immemorial been excluded.⁴⁷

Evidence of the power of this experience does not present itself very well in interview material. It is something one sees in practices, in the personas people inhabit when the meetings commence, in the gravity and seriousness that sometimes take hold. The newfound pleasures of civic virtue should not be underestimated. That they have formed around a medical technology lends the technology itself a significance that transcends its medical uses. It is quite possible that these forums have been so quickly and pervasively feminized in part to protect an activity that has become deeply valued.

AIDS medicine and upward mobility

There is another use to which women have put these feminized spaces. In his book, *AIDS, Politics and Music in South Africa*, Fraser McNeill describes what he saw at the eighth birthday party of an HIV/AIDS peer education project in a rural village in Limpopo, South Africa's northern-most province. The marquee was stuffy and hot, the list of speakers far too long, the speeches they delivered rambling and formulaic. The audience was restless. Just as a representative from the local police station took the podium:

⁴⁷ The most celebrated analyst of this experience is Hannah Arendt. See, *inter alia*, Hannah Arendt, *The human condition* (University of Chicago Press, Chicago, 1999), chapter 24.

A car drew up outside and four women in very expensive *minwenda* dresses and headscarves walked into the front of the tent, accompanied by ululations that drowned out the policewoman's speech. I recognised them as peer educators from the very start of the project in 1998, whom I had not seen for years. They were now working for the government, in the Department of Public Works, as AIDS counsellors and trainers. When the dignitaries had completed their speeches, the four ex-educators rose to give a brief presentation – more like a motivational speech – on their humble beginnings and their newfound status. As they received rapturous applause at the end of their contribution, a current volunteer leaned over to me and pointed at my notebook. "Write this down," she said. "These women are the *real* peer educators."⁴⁸

The provenance of the project of which McNeill writes predates ART; its aim is prevention, not treatment. But the spirit he so powerfully captures would come to pervade the support groups that arose with ART. The vast assemblage of biomedical terms women would so studiously learn in support groups – CD4 counts, viral loads, the names, pharmacological actions and side effects of many drugs and their various combinations – signalled newly acquired technical knowledge on the back of which women hoped to advance.

In the time I spent with support group members in Lusikisiki, the subject was ubiquitous. Everyone had plans, and everyone spoke to me about them incessantly. Nobody imagined that she would be living in her local town or village next year or the year after. The work people hoped to acquire was sometimes concrete and easily envisaged: a pharmacist's assistant at a large city hospital, a sponsored place in a nurse training college. At other times they were vague. 'The longer I stay active in the support group,' one informant told me, 'the more I will learn. If I stay long enough, something will come my way.' Here is another purpose to which women put these new feminized support groups: they were a space in which the technologies of upward mobility might be acquired; all the better if these technologies were available only to women.

To understand the full import of this dynamic, it is necessary to widen our lens. Since coming to power in 1994, the ANC has consolidated its support across much of rural and small-town South Africa at extraordinarily high levels.⁴⁹ An account of the ANC's electoral hegemony in the countryside has yet to be written, but it is clear that support for the party is made possible in part by the various forms of upward mobility that have evolved in rural South Africa since the inception of democracy. It is true that much of the countryside remains poor, but income mobility in the rural South African countryside nonetheless gathered significant pace after the beginning of the democratic era, and most people in most villages have seen somebody get ahead.⁵⁰ The ANC has managed to associate itself with much of this upward mobility, largely because of its incumbency. The rapid expansion of social welfare transfers to the very poor has seen the growth of locally owned small businesses in

⁴⁸ Fraser McNeill, *AIDS, politics and music in South Africa* (Cambridge University Press, Cambridge, 2011), p. 114.

⁴⁹ Collette Shultz-Herzenberg, 'South Africa's 2014 national and provincial elections' (Report, Hanns Seidel Foundation, Johannesburg, 2014).

⁵⁰ Arden Finn and Murray Leibbrandt, 'Mobility and inequality in the first three phases of NIDS' (Working Paper Series Number 120, South African Income Dynamics Study (NIDS), University of Cape Town, 2013).

communities once more uniformly poor. People who for generations have been peasants or miners have ushered children into white-collar civil service jobs. Nationalism in the countryside is animated by the powerful desire for generational improvement.

Indeed, it is probably from the visibility of this new mobility that the ANC has garnered much of its legitimacy. Long before South Africa's democratic transition, Albert Hirschman noted an interesting paradox: post-revolutionary societies are often remarkably tolerant of growing inequality. Why so? Mainly because those left behind feel bonded to those on the way up and can thus take an imaginative journey on their coat-tails. Paradoxically, new inequalities are thus celebrated, at least for a time, as revolutionary achievements.⁵¹

ART support groups have been absorbed into a larger nationalist canon of post-revolutionary upward mobility. They are yet another government-run site that promises personal advancement. The support groups thus inhabit a twilight zone. They are simultaneously many things. They are assemblies of equals who gather to discuss matters in common; yet they are also obligatory patient programmes administered by government. They are sites of voluntary labour to the extent that many of their members fill various layperson functions in administering ART; yet this voluntary labour is done for the state in the hope or the expectation of a permanent place in the bureaucracy. AIDS medicine has become one of the many instruments through which the ANC government exerts soft power over the lives of the rural poor, binding them into a national project of expectation. Many of those in support groups, it would appear, are participating less in an economy of resentment and suspicion than in an economy of hopeful anticipation.

Conclusion

This seems a good moment to return to the beginning, to Fassin's and my respective ethnographic endeavours in the early years of AIDS treatment. The material I used to put together the account you have just read was gathered between 2005 and 2007. I "gathered" it, but somewhat blindly, for I understood its import in retrospect, under the instruction of subsequent history.

Much the same can be said of Fassin's fieldwork. Being a thorough and rigorous ethnographer, he notes enthusiastic encounters between ordinary people and AIDS medicine, but he does not incorporate them analytically, as it were. He records, for instance, that for some, illness has become a social resource: a means to access a disability grant for one, a route to militancy and public action for another.⁵² Yet he does not see that untold numbers of people will use their illness in these ways and that their doing so will come to shape a country's response to an epidemic. He also grants that 'those who encounter certain humanitarian organisations or participate in clinical trials will have access to antiretroviral

⁵¹ Albert Hirschman, *Essays in trespassing: Economics to politics and beyond* (Cambridge University Press, Cambridge, 1981), pp. 39-58.

⁵² Fassin, *When bodies remember*, p. 225.

treatment, opening them to the possibility of a longer life...' But, he continues, 'if one compares the numbers of members of support groups and of patients seen in health facilities to the expected numbers given the statistics of the epidemic, one may assume that the category of the "invisible" is by far most numerous.'⁵³ While this is true, if Fassin is penning these words in about 2004, he has misread the near future. Upwards of three million people will get ART and become members of these support groups. They will do so, not under the auspices of 'certain humanitarian organizations' or in clinical trials, but in state-run clinics.

What is it that these early ethnographies missed? I was perhaps led by a personal disposition that attracted me to difficulty and to internal turmoil. My thoughts were most stimulated by those whose responses to ART were tortured. Fassin's case, it seems to me, is both more interesting and more sympathetic. His book is written against self-satisfied Western commentators who declared Mbeki a dissembler or a madman, revealing an astonishing incapacity to see the past through Mbeki's eyes. Fassin bristled in the face of such views, and understandably so. He wanted to show that Mbeki could be understood, but only by those brave enough to make the great moral effort to comprehend the world as the dominated do.

These are noble motives. But to the extent that he swept up the feelings and responses of ordinary people into his account of Mbeki's views, he painted too simple a picture. Resentment and suspicion were certainly among the reactions of ordinary people to the new medical technologies associated with AIDS, but the poor are a complicated bunch and their responses to new technologies are varied. Fassin argues that the reactions of ordinary people to AIDS paralyze action, for 'dominated people ... are caught up in a powerlessness that they justify by their history'. This is too sweeping a statement; it requires heavy qualification. The evidence suggests that many ordinary people, especially women, responded creatively to the new technologies they encountered and bent them to their own purposes.⁵⁴ Nor was the ANC's nationalist project caught in the paralysis Fassin describes. It seemed, in the end, to divest ART of its connotations of subordination and resentment and, instead, used ART to exercise soft power.

⁵³ Fassin, *When bodies remember*, p. 240.

⁵⁴ Existential anthropologists have indeed argued powerfully that insofar as people act they forget those parts of their histories that rendered them powerless. See especially, Michael Jackson, *Existential anthropology: Events, exigencies and effects* (Berghahn, New York and Oxford, 2008).