

FINDING THE MEANINGS OF AIDS

ARV treatment in an Eastern Cape village

Jonny Steinberg
jonny@number301.com

What happens to the meanings of AIDS when treatment for it becomes universally available? The author asks this question in Lusikisiki, where a successful antiretroviral treatment programme in the district's 12 clinics made treatment accessible. The most profound effect is a whittling away of public denial. As nurses begin successfully treating opportunistic infections, so villagers' definition of AIDS broadens considerably; infections previously considered the work of witchcraft are now identified with AIDS. However, two years after the beginning of treatment, AIDS remained highly stigmatised. Although everyone knew where to go for treatment, some stayed at home and got sicker, while others tried to initiate treatment secretly. The future of the meaning of AIDS depends a great deal on whether the health system can maintain the quality of its service. If radically understaffed clinics begin finding ways to turn patients away, people will look increasingly to traditional and lay-healers for treatment and accept alternative explanations for illness.

What happens to the public meanings of AIDS when a successful antiretroviral treatment (ART) programme is established in a community in which AIDS was previously untreatable? This is precisely what happened in the Eastern Cape town of Lusikisiki. Until early 2003, AIDS was a terminal disease for all in this rural town save for a handful of its middle class residents who could access drugs on their medical aids. Then an ART programme run by a partnership between the international non-governmental organisation Médecins Sans Frontières (MSF) and the Eastern Cape Health Department was established in the district's 12 clinics. By the first quarter of 2006, 110 people were being initiated onto ART every month, matching the rate at which people were falling ill with Stage IV AIDS. Within three years, access to ART had moved from zero to universal.

For a 16-month period between October 2005 and January 2007, I conducted a qualitative research

project in an outlying Lusikisiki village, which I shall call Ithanga. My aim was to discover what happens to the meanings of AIDS once treatment becomes available. This article is a summary of some of my research findings.¹

Lusikisiki and Ithanga

Lusikisiki's population of 150 000 people is dispersed across about three dozen villages and a town centre. It is socially and geographically diverse. The villages close to the centre of town were all electrified in the early 2000s. They are serviced by decent roads and a fixed line telephone service. Most are in walking distance of a clinic. Some of the houses along the streets are home to well-off middle class families.

Just 20 or 30 kilometres away, some of Lusikisiki's outlying villages have no electricity, no navigable roads, and no running water. The nearest clinic is often an expensive and time-consuming taxi ride away. Most people live in mud and cement homes

they built with their own hands. Fresh water is carried from the nearest river.

Ithanga, the site of my research project, is one of these outlying villages. It is about 30km from the centre of Lusikisiki. Its population of 600-700 people have no electricity and no running water. Until about a generation ago, the primary source of employment for the village was the Witwatersrand's gold mining industry. As is well known, the industry's labour force contracted rapidly and permanently in the late 1980s. Today, the village's primary source of income consists of state pensions, survivalist self-employment and short-term wage labour.²

Ithangans would not have heard of ART before MSF's Lusikisiki project. And, as an outlying village, they would have heard about it later than most of Lusikisiki's people. The nearest clinic is some 15km away. The majority of Ithangans would have first heard about ART in the form of rumours and news from villages closer to the centre of town.

The ART programme

Before examining the response of Ithangans to the arrival of ART, I will first describe the programme itself. It constituted a bold innovation in AIDS medicine, inasmuch as it aimed to deliver ART through primary healthcare clinics rather than hospitals, and was to be administered by nurses and lay people rather than doctors. Indeed, MSF is an outspoken advocate of the idea that South Africa will only achieve universal access to ART if treatment is primarily clinic-based, and nurse-initiated. Their argument is twofold. First, the extent of the epidemic is so great that if treatment is confined to hospitals, programmes will soon bottleneck and the majority of those in need of treatment will die waiting. Secondly, if people are to adhere to treatment, ART must be as decentralised as possible. At hospitals, patients arrive from distant districts and disappear again; medical personnel can only hope that they will return for their next batch of pills. If treatment is clinic-based, each patient is known to the clinic's lay personnel, and the direct relationship between patient and healthcare provider encourages adherence to treatment, timely reporting of illness, and so forth.

When MSF arrived in Lusikisiki in 2003 the district's 12 primary healthcare clinics were hardly in a state to tackle a great epidemic. Only two had reliable electricity supply, and just one had running water or a phone. Fewer than four in ten nursing posts were filled. Per capita, the district had 14 times more people per doctor than the national average. The majority of clinic nurses encountered by MSF project leader, Hermann Reuter, during his first weeks and months in Lusikisiki, did not believe that there was an AIDS epidemic.

Four years later, these same clinics had conducted 46 000 HIV tests and put 2 200 people on ARVs (MSF 2006). The key to the transformation of these once moribund institutions lay in the recruitment of a cohort of lay people to alleviate the workload of nurses. Adherence counsellors staff each of the 12 clinics: they are trained to perform voluntary counselling and testing, prepare patients for treatment, establish support groups for antiretroviral users, monitor adherence, and collect data. Pharmacy assistants are recruited to dispense medicines, monitor low stocks, and place persistent pressure upstream to supply the district's burgeoning need for medicines. Anti-retroviral users themselves play a significant role, tracing defaulters, recruiting others to test, and giving treatment a public face.

The programme is by no means without serious problems, the most grave of which is personnel shortages. I return to this question at the end of this paper.

AIDS in Ithanga before treatment

My primary informant in Ithanga was a 29-year-old man whom I shall call Sizwe Magadla. I met Sizwe in October 2005. He told me then that he knew of six people in Ithanga who had died of AIDS, all in the last four years. I asked a dozen or so other villagers how many Ithangans had died of AIDS. Some said five, others seven. The majority said six.

It is almost certain, though, that the figure was considerably higher than that, for villagers' standard definition of AIDS before the advent of ART was very narrow indeed. A person was said to have died of AIDS if she contracted chronic diarrhoea that did

not respond to treatment, grew very thin, and died. Yet that is hardly the most common chain of events leading to an AIDS death. Those who displayed other symptoms were generally said not to have died of AIDS. A person who contracted cryptococcal meningitis, for instance, or AIDS dementia, was said to have had a demon sent to him by an enemy. A person suffering from shingles – a common opportunistic infection triggered by immunodeficiency – was said to have had a witch's snake crawl over her skin while she slept.

It was common cause among informants that those who were known to have died of AIDS were thought to have died shameful deaths. The four most common answers to why AIDS deaths were shameful were these:

- 1) People say X got AIDS because she (or he) slept around.
- 2) People say X brought AIDS home and has probably given it to her husband (or his wife).
- 3) People say that because X cannot control her (or his) sexual appetite, she is killing the people close to her.
- 4) People say X knew she had AIDS and slept around to take as many people as she could with her to the grave.

In other words, the accusation is that X has been sexually gluttonous, and as a result, has endangered the lives of, or perhaps even murdered, her loved ones.

Testing day

ART arrived in Ithanga abruptly on a Saturday morning in February 2005. A group of nurses and lay counsellors set up a mobile centre at the local school to offer voluntary counselling and testing (VCT) for a day. In the preceding weeks, lay counsellors had met with the local chief to obtain his permission to perform VCT in the village, and had then gone door to door to inform residents of their plans. By Saturday morning, most Ithanga residents knew that they were coming.

During the course of testing day, some 200 hundred Ithangans drifted to and from the school. Most had not come 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 Sizwe explains it: 'To know, you just had to stand and observe. You looked for how long the people stay. You see, 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. By the time the day ended, the whole village knew who had tested HIV-positive.'

MSF personnel were of course acutely aware that the testing process was hardly private. They did not want AIDS to be hidden, primarily for two reasons. First, they wanted communities to see for themselves how extensive the epidemic was, and thus to banish denial. Second, MSF believed that this fish-bowl approach to testing was the best way to combat stigma. Their message to those who walked into their testing centres was this: yes, there is ill feeling out there, but it doesn't matter. Yes, your community will know your status, but you will be okay. Once you realise that the hostility will not hurt you, you will have walked through an invisible barrier. You will have shaken off an unspeakable burden and an intolerable pain. Come with us, there are many of us, we have support groups, we have formed networks of HIV-positive people, and you will be safe and will find meaning in those networks.

On that Saturday morning in February 2005 about forty people went to the school to test for HIV, the majority of them young women. By the end of the day, nine women had been identified as having tested HIV-positive.

As news circulated, Ithanga went into a state of collective shock. In the course of a few hours, nine healthy, ordinary-looking villagers, most of them young women, had been marked with death. Ithanga had just had its first taste of what it means to live in the midst of a disease that banks itself invisibly in the bodies of the young and the healthy.

Such information is not easily absorbed. In the weeks and months that followed, those who had tested positive were watched. Nobody told them that they were being watched. Nobody said to their

faces that their status was common knowledge. But everything about them was observed in meticulous detail: whether they coughed, or lost weight, or stayed at home ill; whether they boarded a taxi, and if so, whether that taxi was going to the clinic; above all, with whom they slept. These observations were not generous; they issued from a gallery of silent jeerers.

In essence, Ithangans were using their knowledge of the nine villagers' HIV status to fuel their sense of denial. By putting an invisible fence around the nine women and silently jeering at them, the village was in effect putting a fence around AIDS.

After testing day

Such was the immediate aftermath of testing day, but what were some of the more long-term effects?

I discerned two, and was interested to note that they appeared at first sight to sit uncomfortably together. The first is that ordinary villagers' definition of AIDS expanded considerably. As Sizwe explained 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* went to the *inyangas* 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 AIDS. They were given the drugs for their skin and they got better.'

Similarly, villagers began noticing that 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. Thus, in the wake of testing day, villagers' definitions of AIDS expanded dramatically; people saw much more of AIDS around them than they had in the past.

And yet, the fact that lay definitions of AIDS broadened, and the fact that this broadening was closely associated with the diagnostic and palliative competence of allopathic medicine, did not translate smoothly or simply into an endorsement of the efficacy of antiretroviral drugs. One's attitude to treatment is determined as much by what one feels as what one sees. And what one feels is shaped in

large part by whether the pills themselves are associated with shame or with pride, with resignation or with confidence, with danger or with hope. And these things are all determined in no small part by the sort of face the healthcare system presents when it comes to test, by whether the clinics are clean, efficient, and user-friendly, and their staff competent, by whether one feels safe and cared for there, and by the sorts of communities ARV-users form.

In my experience of Ithanga, a minority of those who started treatment associated the pills unambiguously with life. They celebrated and were thankful for the pills. They exuded no shame. Generally, they had a warm relationship with the nurse or adherence counsellor or community health worker who guided them on to treatment, and they associated treatment with that person. Yet many other people associated the pills with the danger of being exposed and shamed. Nobody wanted what had happened to those nine young women in February 2005: nobody wanted to test positive before the eyes of their community.

My last field trip to Ithanga was in April 2007, more than two years after treatment came to the village. The 16 or so people I knew to be chronically sick and whom I interviewed could be divided into three categories. The first were openly on ARVs, had embraced them as a life force, and were largely unhurt by the silent and ungenerous thoughts and whispers of fellow villagers. A second category would not go to the clinics to have their CD4-counts taken or to begin treatment. Some had long ago tested positive for HIV. Others had never tested. They either stayed at home, or visited traditional healers, or visited one of the general practitioners in town who is happy to collude with his patient and never mention the word AIDS, while charging a fee for treating symptoms. Their situation was especially tragic, for their condition was hardly a secret. With its newfound diagnostic knowledge of AIDS, the community of Ithanga now recognised AIDS when they saw it. And so several people were wasting away and dying before their neighbours' eyes. Everyone knew it was AIDS, but most were discreet. The dying were afforded their right to denial over the right to life that they themselves had lost sight of.

The third category of the chronically ill did visit the clinics and either went on to treatment or expressed a willingness to do so when the time came. But they attempted to do all of this secretly. Most tried to avoid the clinic nearest to Ithanga for fear of being recognised. They would generally try to enrol at the clinic in Lusikisiki's town centre, or, if they could not avoid the local clinic, they would try to go there unseen.

Conclusion

Two years after the initiation of ART in Ithanga, much had changed. Most villagers now knew and recognised the most common opportunistic infections associated with AIDS; the definition of the syndrome had thus expanded considerably, and the space for denying its prevalence had shrunk. Moreover, the number of people on treatment had grown steadily. By early 2007, as many as two dozen villagers, perhaps more, were on ART. Everybody in the village knew where to go to test and to get on to treatment. These are considerable achievements.

What had not been achieved, though, was the normalisation of AIDS as an ordinary chronic illness. Many people were still dying before the eyes of their families and neighbours because they could not cope with the prospect of acknowledging that they had AIDS. The acute sense of shame associated with it had shifted, been displaced, and found new forms, but it was far from eradicated.

Perhaps the most important factor in shaping the future of the meaning of AIDS in Ithanga is whether the quality of ART can be maintained. In early 2006, Lusikisiki's clinics were putting 110 people on treatment every month, despite the fact that more than half of nursing posts were vacant and unadvertised. Workloads were climbing steadily. Before the ART programme began, a Lusikisiki clinic nurse saw an average of 27 patients a day. At the height of the ART programme, the figure had climbed to 49 (MSF 2006). Whether chronically understaffed clinics can maintain that sort of workload is questionable. MSF was the programme's inspiration and moral champion. It left Lusikisiki, as intended, in late 2006. It is quite possible that in its absence, the system will find

informal ways to manage its workload by bringing down patient numbers. If, in the coming months and years, ART becomes more difficult to access, people will increasingly look elsewhere for succour and for treatment. As this happens, the currency of the biomedical diagnoses of, and explanations for illness that have become associated with successful treatment, will begin to weaken.

References

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Endnotes

- 1 The project produced two much longer documents: a book and a monograph. See Steinberg 2008 and 2007, respectively.
- 2 For a survey of survival strategies in two outlying Lusikisiki villages, see Hajdu 2005.