

# Aids and Aids treatment in a rural South African setting

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# 1 Introduction

The purpose of this monograph<sup>1</sup> is to explore changes in the public meanings of acquired immune deficiency syndrome (Aids) and health-seeking behaviour when a successful antiretroviral treatment (ART) programme is established in a community in which Aids was previously untreatable.

The place in question is Lusikisiki in the Eastern Cape. It is among the poorest and most densely inhabited rural districts in South Africa. It consists of some three dozen villages scattered in a wide radius around a town centre, and it is home to about 150 000 people. While parts of South Africa have been harder hit by the Aids epidemic than Lusikisiki, Aids remains the single gravest public health catastrophe the district has experienced in living memory. The rate of human immunodeficiency virus (HIV) prevalence among pregnant women is about 30 per cent. According to the best actuarial models, about 110 people in Lusikisiki enter Stage IV Aids every month (*Médecins sans Frontières* 2006). Anecdotal evidence I collected during my fieldwork between October 2005 and February 2007 suggests that an average of at least one person dies of Aids every day in the medical wards of the regional hospital in town. The last time young and middle-aged adults were struck down in comparable numbers was during the 1918 flu epidemic.

In early 2003, the international nongovernmental organisation (NGO) Médecins Sans Frontières (MSF) launched an ART programme in Lusikisiki in partnership with the Eastern Cape Department of Health. The programme is distinctive because treatment is administered from primary health care clinics, not hospitals; and by nurses, not doctors. The doctrine underpinning the programme is that in the context of an epidemic as pervasive as this one, and with shortages of medical personnel as chronic as they are, treatment will reach everyone who needs it only if it is as decentralised as possible and if the enormous burden of treatment provision is distributed among nurses and laypeople.

When MSF launched the programme in 2003, about 60 per cent of nursing posts in Lusikisiki's 12 clinics were vacant. Drug supplies were erratic, and most of the medicines listed on South Africa's Essential Drugs List had never made their way to Lusikisiki's clinics at all. Only one of the 12 clinics had electricity, one had running water, and none had a working telephone or fax machine.

Within three years, 46 000 HIV tests had been performed in Lusikisiki and 2 200 people had begun ART. About 100 people a month were initiating treatment, which meant that the rate of treatment had begun to match the rate of illness. It was an extraordinary feat but also a precarious one, for questions about its sustainability have arisen. I document these questions later.

The monograph's primary question is the following: within a short time, Lusikisiki was transformed from a place in which almost no Aids treatment was available, and Aids was thus a terminal illness, into a place where ART was universally accessible. What did this transformation do to the meaning of Aids in Lusikisiki? Is it becoming less stigmatised? Are some of the darker and more pernicious meanings attached to it beginning to disintegrate? Most importantly, are the ill coming forward for treatment or are significant numbers staying at home and dying?

There is, of course, a subtext to these questions. The epidemic has been as hard on the health of souls as it has been on bodies. The shame and accusation it has unleashed have come to constitute a large quotient of the social ill associated with it. Some claim that the social pathologies attached to Aids are primarily a function of the absence of decent medical care and that once people witness that Aids is treatable, the social poison associated with it will dissipate.<sup>2</sup> Others suggest that shame and accusation may be bound inextricably to Aids and will prevent sizeable numbers of people from coming forward for treatment, even when it is readily available.<sup>3</sup>

Judging by available empirical evidence, the jury is still out. There is no shortage of reports of people who live within walking distance of treatment dying in their homes. The question is why. Is it because particular programmes are poorly designed, inadvertently deepening people's shame and thus scaring them off? Or will no programme ever be good enough? Are multitudes of people destined to die of shame and stigma despite the availability of treatment?

This monograph examines one place and marks the changes the meaning of Aids and the behaviour of people underwent as treatment became available. To the extent that there are universal lessons to be learnt, they will be teased out.

The monograph is divided into four chapters and two appendices. The first chapter explores popular meanings and definitions of Aids in Ithanga, the outlying Lusikisiki village where I conducted much of my research before the arrival of ART. Chapter 2 describes the arrival ART in Ithanga. It charts how ART exposed the prevalence of the epidemic for the first time, dramatically expanded ordinary people's definitions of Aids, and began altering treatment-seeking behaviour. Finally, it examines the effects the availability of treatment had on stigma. Chapter 3 examines aspects of political and cultural resistance to ART. Chapter 4 describes how Lusikisiki's clinics became institutions capable of administering ART and explores the difficult question of the sustainability of the service they provide. In the form of a case study I show how the quality of service delivery profoundly shapes the meaning of Aids, the nature of stigma, and treatment-seeking behaviour.

Finally, there are two appendices. My Lusikisiki research has produced sufficient material, I believe, to make useful contributions to two specific debates in the Aids literature: first, the relationship between HIV stigma and sexual shame; and second, the relationship between HIV and witchcraft. Appendix 1 deals with shame and Appendix 2 with witchcraft.





# 2 Aids before treatment

This chapter examines the meanings of Aids in public and private discourse in an outlying Lusikisiki village prior to the arrival of ART.

## **DIFFERENT FACES OF LUSIKISIKI**

Despite its relatively small population and its remoteness, Lusikisiki 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: they sport a good car or two in the driveway, a satellite dish, electrical appliances in the kitchen and a full-time domestic worker. Many of these families have a long middle-class pedigree: several generations with university degrees and family members in the upper strata of government, business and professional life. Members of a cosmopolitan, bourgeois elite are scattered throughout the villages around town.

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. The bodies of the dead are carried to their burial places on the backs of oxen. Fresh water is carried from the nearest river. Many middle-aged villagers have never watched television or read a newspaper. Some of the women have never travelled further than the centre of Lusikisiki.

When one explores what Aids meant before the availability of treatment in Lusikisiki, it is important clarify whom one is talking about and where they live. Members of elite households around town would generally have been aware of ART before it came to Lusikisiki. Many would have had access to it, whether through private care or through dual residencies in cities such as East London or Durban.

For residents of many outlying villages, in contrast, ART was entirely unknown before its arrival in Lusikisiki. They would have heard of it for first time through the oral transmission of news, perhaps when nurses and laypeople came to the local school to conduct voluntary testing and counselling (VCT) or through a rumour that an ill neighbour went to the clinic and came home with medicine.

## **ITHANGA**

The greater part of my fieldwork was conducted in a Lusikisiki village that I have called 'Ithanga'. It is an outlying village some 30 kilometres from the town centre, and it is home to 700 to 800 people. It is among the Lusikisiki villages that have benefited least from 13 years of democracy. By the time I completed my fieldwork in early 2007, the village still had no roads, electricity or running water. The nearest clinic was about 15 kilometres away and could only be reached by taxi. There was a local school, but it only went up to grade nine. To finish secondary school, an Ithanga teenager would have to leave the village and live with relatives or friends in a village closer to town.

Ithanga is one of those villages whose residents would not have heard of ART before it came to the clinics of Lusikisiki. Before the arrival of the treatment programme, Aids was regarded as untreatable by allopathic medicine.

Two generations ago, Ithanga's chief source of income was the wages remitted home by migrant workers. When they came of age, most young men would travel first to the Natal sugar fields and then, when they were a little older, to the Witwatersrand goldmines to work. Most would marry in Ithanga. They would

remit much of their wage back home to support their Ithanga household, which would own cattle and grow an assortment of rainwater vegetables.<sup>4</sup>

This political economy began to erode in the late apartheid years and collapsed entirely in the late 1980s and early 1990s when the gold mining industry shed some 40 per cent of its labour force. Today, the relationship between Ithanga and South Africa's metropolitan cities has changed in paradoxical ways. On the one hand, they are much closer. Major cities like Durban, East London and even Johannesburg are just a taxi ride away. On the other hand, they are less accessible to present generations than they were to previous ones inasmuch as young rural people struggle to find work there. Today, young men and especially young women from Ithanga are better travelled than their grandparents. Most periodically journey back and forth between Ithanga and urban centres, yet they are more likely to be unemployed. Although an employment and livelihoods census has never, to my knowledge, been conducted in Ithanga, studies have been done in similar neighbouring villages. A household survey conducted in a village very similar to Ithanga indicated that a third of all households relied solely on state grants and a further 38 per cent on a monthly wage of between R500 and R700 (Hadju 2005:246; 2006).

We shall see later that Ithanga residents closely associate this pattern of rapid, workless and circular migration with Aids. It is said that young people, and especially young women, brought the disease back with them from the city.

## AIDS, WITCHCRAFT AND AMBIGUITY

My primary informant in Ithanga was a 29-year-old man whom I shall call Sizwe Magadla. He grew up in Ithanga, as did the last four generations of his paternal forebears. When I met him, he was a fledging businessman and owner of a nine-month-old spaza shop and tavern. By the time I completed my research 18 months later, his business had prospered and he was on his way to becoming one of the wealthiest people in the village.

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 previous 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, however, that the figure was considerably higher, 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 he or she contracted chronic diarrhoea that did not respond to treatment, grew very thin, and died. However, that is hardly the most common chain of events leading to an Aids death. Those who displayed other symptoms leading to an Aids death were generally said not to have died of Aids. For instance, a person who contracted cryptococcal meningitis, or Aids dementia, was said to have had a demon sent to him by an enemy. Another 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.

I asked Sizwe and others whether they had discerned an increase in deaths due to witchcraft in recent years. I received an assortment of answers. Middle-aged and elderly people generally said that incidents of witchcraft had increased in recent years. They attributed this phenomenon to cultural atrophy. In the old days, they said, people were responsible with dangerous medicines. Today, a youngster can buy poison on the open market. In contrast, young people generally said that they believed witchcraft had declined in recent years. Ironically, they also attributed this trend to cultural atrophy. Witches and wizards, they said, draw their knowledge and their strength from cultural tradition. As tradition crumbles, practitioners of witchcraft grow less competent.

Although people believed that only six villagers had died of Aids, everybody spoke of Aids as a pandemic to be deeply feared. There are probably several explanations for this paradox. One is that the boundary in people's minds between an Aids death and a non-Aids one is, in fact, far hazier than one might imagine if one merely asked the question, 'How many people have died of Aids?' As the questions about certain deaths became more specific, it became apparent that the issue of Aids did, in fact, lurk menacing in the background to every death of young or middle-aged persons.

For instance, Sizwe lost his best friend to illness in 2001. I shall call him Jake. Jake was an unusual Ithangan inasmuch as he had a full-time job, one that was very well paid by Ithanga's standards. He was a gold miner. He was a conscientious saver and invested much of his earnings in cattle. He was also conspicuously generous: when he came home for Easter and Christmas, he showered gifts upon loved ones and friends.

Jake grew ill some two years before his death. Among his symptoms was an agonising skin infection that began above his pelvis before progressing to his groin and genitals. It was assumed among those close to him that he been

bewitched by an uncle who was jealous of his success. His skin infection corresponded to a well-known form of witchcraft. The jealous one purchases a medicine and surreptitiously puts it in his victim's lover's food. The next time the victim has intercourse with his lover, he imbibes the poison. His illness begins with a rash in the two tiny indentations between the hips and the pelvis. From there it spreads to the groin and the genitals.<sup>5</sup>

Sizwe nursed Jake while he was ill. When he was close to death, Jake confided in Sizwe that he had been tested for HIV on the mines and that the doctor had told him he was positive. He made this acknowledgment in a moving and complicated way. Sizwe has long dreadlocks of which he is very proud. Sizwe recalled that Jake, lying on his sickbed, pointed at Sizwe's hair and said, 'You are a Rasta. Look at your hair. You are a Rasta.'

Sizwe said: 'Yes, I have dreadlocks.'

'You are a Rasta,' Jake said. 'Nowadays, the times are bad. Your dreadlocks talk. They say you are looking for girls. They say you are beautiful and you want girls. This hair of yours is attracting girls because you are looking beautiful.'

'I understood what he was saying,' Sizwe told me. 'He was in trouble. In his mind, his trouble was becoming my trouble. He was so angry. He was so upset. He was looking at me and crying. He was desperate to protect me. He pleaded with me to cut my hair.'

Jake was telling Sizwe that he had contracted his illness through sex and not through witchcraft. He set aside his shame and broke his silence in order to issue this warning to his close friend: 'Don't believe it was witchcraft; look after yourself.'

Publicly, then, it was common cause that Jake had died because he was bewitched. Privately, the story was far more ambiguous, the line between an Aids death and a bewitchment death much less distinct. I believe this to be true, not only for Jake's death but also for the majority of those of young and middle-aged villagers. The more intimate one's relation is to the deceased, the less certain the cause of his or her death.

## **AIDS, SHAME AND ENVY**

It was common cause among informants that those who were known to have died of Aids were thought to have died shameful deaths. Answers to why contracting Aids was shameful depended very much on the phrasing of the

question. When I asked, ‘Would you keep it a secret if you contracted Aids?’ almost all informants said yes. Asked why they would do so, most replied that if it were common knowledge that one had Aids, one would be weakened in the face of those who wished one ill. As one informant put it, ‘I have lived in this village all my life. Everybody here has known me since I was a child. Among those people, some are angry with me. Others are jealous of me. If it was known I had Aids, I would be defenceless. Everyone who has ever wanted to show me scorn but had been unable to would show me scorn now.’

Indeed, Sizwe told me that if he tested HIV-positive and the village came to know the results, those who envied him his success would be in a position to destroy his business. When I asked how they would do it, he could not describe a concrete set of circumstances but this did not diminish his certainty that he would be sufficiently weakened for his enemies to destroy him.

However, turning the question around elicited a very different response. When the question I asked referred to others contracting Aids rather than to oneself, in other words, ‘Why was it shameful that X died of Aids?’ the most common answer was framed as a series of accusations:

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

In other words, X has been sexually insatiable and the result is that she (or he) is killing her (or his) spouse and leaving her (or his) children orphaned.

As is clear from this answer, as well as from Sizwe’s account of Jake’s secret admission that he had tested HIV-positive, Ithanga residents firmly believed that when persons were said to have died of Aids, they had died from a sexually transmitted disease and not from witchcraft. Moreover, the shame they suffer is a sexual one and the accusation is that their sexual excess has resulted in their and others’ deaths.

The matter is not that simple, however. While all informants agreed that HIV was sexually transmitted, most also believed that demons could transmit

HIV. For instance, a witch could instruct her demon to contract HIV and then tell him to have sex with her enemy. 'An infected demon will come and have sex with you while you are sleeping. If you are a man, you will know that you have had sex with a demon during the night if you wake to discover that you have ejaculated into your linen. If you are a woman, you will know because there will be scabs of dried semen on your thighs.'

There is another way a demon may infect you with HIV: by taking blood from an HIV-positive person while she is sleeping, coming to your room, and injecting it into your blood while you are asleep. Several informants told me that household members have woken in the morning to find a bruised arm or razor blade cuts at the joints. They suspect that a demon has come to transmit HIV.

Generally, the transmission of HIV by demons was invoked to defend the dignity of a person who had contracted Aids: 'X did not sleep around. Either she got it from her boyfriend or a rival sent a *tikoloshe* to infect her with Aids.' In other words, demon-transmitted HIV was invoked as a bulwark against shame.

In any event, it seems that the two primary feelings triggered by Aids are shame and envy. A person who has contracted Aids did so either by acting shamefully or by being envied. Shame and envy have strong resemblances. The former is a manifestation of hostility one feels towards oneself, a feeling that one is rotten, indecorous or dishonoured. The latter is an expression of hostility levelled from the outside by others. It is perhaps the most poisonous of all categories of hostility since it expresses a desire not to covet or to steal what one has but to destroy what one has.<sup>6</sup>

In either case, whether one is shamed or envied, Aids is associated either with murder or with culpable manslaughter. A person who contracted Aids from a demon has died at the hands of another. A person who contracts Aids because he or she is sexually gluttonous and then transmits it to another has killed somebody as a result of an intolerable weakness of character. As the meaning of Aids shifts from shame to witchcraft, as blame shifts from the infected individual to those who envy him or her, that which is displaced from one object to another, but is never erased, is accusation.

Such was the state of the meaning of Aids in Ithanga, insofar as people were able to remember it when I did my fieldwork, before the arrival of treatment.





# 3 Treatment in Ithanga

## PRELUDE TO 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 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 from door to door to inform residents of their plans. By Saturday morning, most Ithanga residents knew that they were coming.

Compared to most Lusikisiki villages, Ithanga was late in receiving ART. The programme's first patients began treatment in October 2003. Ithanga was late because it is remote: it is 15 kilometres from the nearest clinic and it is surrounded by dense forest. MSF decided to erect a mobile VCT centre precisely there because the organisation knew that it was the kind of place that would fall through the treatment programme's cracks.

Because ART arrived late, most villagers had heard rumours about it. The most dramatic was that the needles used to perform the blood test were laced with HIV and that the programme itself was part of a conspiracy to decimate blacks. The origin of the rumour was the following: the head of the treatment

programme was a white MSF doctor named Hermann Reuter. When he arrived in Lusikisiki, most clinic nurses he spoke to told him that they seldom saw HIV in Lusikisiki. He believed his first task was to show them the scale of the problem he would be asking them to manage. At each clinic, he erected a VCT centre, performed the testing himself and made the nurses watch the results, one by one.

From this spectacle, a rumour began circulating among the villages of Lusikisiki that a white man called Dr Hermann had been going around the villages giving people HIV. He was, according to the rumour, part of a conspiracy to kill blacks until whites were once again an electoral majority. The aim of the conspiracy was to bring FW de Klerk back to power.

Reuter was openly confronted with this accusation at two clinics. He responded by performing the test on himself, carefully explaining the science of it. Elsewhere, according to a lay counsellor, 'people did not confront him openly about it, but when they heard he was in the village, they came to watch. They wanted to see with their own eyes this doctor who had come to kill the people.'

As Reuter said, 'At the beginning, only the very sick came to be tested. They knew they were dying and so they had nothing to lose.'

By February 2005, the rumour had largely abated in the more central villages of Lusikisiki. Enough people had witnessed sick neighbours and family being successfully treated for opportunistic infections to understand that Reuter was a healer. The clinic waiting rooms were packed with people coming to test for HIV, and Reuter had become a respected and trusted figure.

However, in remote villages such as Ithanga the rumour persisted and therefore many villagers who assembled at the school that Saturday morning did not come to test but to see whether Reuter himself would make an appearance. They wanted to judge for themselves whether he was benign or malignant. They were to be disappointed. He was not there. The mobile unit was staffed by two black nurses and about half a dozen young black lay counsellors.

Other rumours that had circulated in Ithanga before testing day were less dramatic and more open-ended. Some people had heard of a new treatment available at the clinics that did not work; they had been told of people who had started taking the pills and had died anyway. Others had heard of very ill people taking the pills and rising from their deathbeds several weeks later. What everybody understood was that the pills were not a cure and would have to be taken twice daily for the remainder of the patient's life.

## TESTING DAY

During the course of testing day, some 200 hundred Ithangans 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 Sizwe explains, ‘To know who was positive and who was negative, 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. They don’t come out for maybe half an hour, even an hour. And then you know. 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 they had established was hardly private. This was partly deliberate. First, they wanted communities to see for themselves how extensive the epidemic was. ‘Once you see with your own eyes how many healthy-looking people are HIV-positive,’ Reuter told me, ‘it really begins to sink in for the first time that you are living in the midst of a very serious epidemic.’

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 will protect you.

As Hermann Reuter said to me, ‘A person goes to test. If he tests positive, the people in his community will know, and he will make some enemies. But the friends he makes will be more important than the enemies. The people testing positive develop meaningful relationships, the sort of relationships they have never had. Before, they were sitting around and doing nothing. Now, their lives become meaningful.’

Whether this is the most effective way to get people to test and onto treatment and whether it is sufficiently cognisant of the right to privacy are questions about which there will always be a reasonable amount of disagreement.

In any event, on that Saturday morning in February 2005, about 40 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 the 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, its first experience of an epidemic without determinable boundaries, an epidemic that may reside in just about anybody one claps eyes on, including oneself.

Such information is not easily absorbed. In the weeks and months that followed, those who had tested positive were silently separated from the rest of the village. They were watched. Nobody told them that they were being watched. Nobody said to their faces that their status was common knowledge. However, 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 barrier around the nine women and silently jeering at them, the village was in effect putting a barrier around Aids. To be one of those who jeer is to avoid being one of those jeered at. To jeer is to defend oneself from the knowledge that the virus has no boundaries and might thus be in one's own blood.

## AIDS AFTER TESTING DAY

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

I discerned two, and was interested to note that at first sight they appeared to sit uncomfortably together. The first effect is that ordinary villagers' definition of Aids expanded considerably. As Sizwe explained, '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 Aids around them than they had in the past. In this respect, MSF's argument that those ill with Aids must be visible is undoubtedly a strong one, for their visibility was instructive, probably guided the treatment choices of many who subsequently fell ill, and thus saved lives.

However, the fact that lay definitions of Aids broadened and 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. On reflection, it is not hard to see why. A curious and unprejudiced villager watching the world around her closely and curiously and examining the empirical evidence for the efficacy of ART in the wake of testing day would come to a mixed set of conclusions. In some cases, she would observe very sick people begin taking the drugs and quickly becoming healthy. However, that is not all she would see. She would in all likelihood divide those she knows to be HIV-positive into two categories: those taking pills and those not. The latter are generally still asymptomatic. All that separates them from other healthy people is the knowledge that they have tested positive. Those on antiretrovirals (ARVs), in contrast, have Aids. Some experience visible side effects to their drugs, especially in the first months. Others are on a long and fitful road to recovery; they frequently fall ill. Still others die. About one in six people who begin ART in Lusikisiki die within a year. Thereafter, mortality rates drop to almost zero. Nonetheless, death is associated with those beginning treatment.

The hypothetical villager is no fool: she knows that the healthy are still asymptomatic and may one day fall ill. Nonetheless, she cannot shake off the doubt that the empirical evidence has instilled in her. What she witnesses over the medium term is that people known to be HIV-positive and to be on the pills are often sick, sometimes mortally so, while those known to be HIV-positive and not on the pills are healthy.

From a bird's eye view, such as a statistician has when comparing mortality in villages with and without treatment, the efficacy of ART is obvious. Of those whose CD count drops below 200 and who do not begin treatment, half are dead within two years.<sup>7</sup> Of those who do begin treatment, more than 80 per

cent are alive two years later.<sup>8</sup> However, that is not what a villager sees, even if she examines the evidence closely and dispassionately.

Given, then, that one's view of treatment is underdetermined by the evidence before one's eyes, one's attitude to treatment is determined as much by what one feels as by what one sees. 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 factors are all determined in no small part by the face the health care system presents when it comes to test: whether the clinics are clean, efficient and user-friendly, and their staff competent; whether one feels safe and cared for there; and by the kind 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 to treatment, and they associated treatment with that person. Yet many people associated the pills with the danger of being exposed and shamed. Nobody wanted to undergo what those nine young women had experienced in February 2005: nobody wanted to test positive before the eyes of their community.

My last fieldtrip to Ithanga was in April 2007, more than two years after treatment had come to the village. The 16 or so people I knew to be chronically sick and whom I interviewed could be divided into three categories. Those in the first category 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. Those in the 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 was happy to collude with his patients and never mention the word 'Aids', while charging a fee for treating their 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 the condition when they saw it. Several people were wasting away and dying before their neighbours' very eyes. Everyone knew the cause was Aids, but most were discreet. The dying were afforded their right to denial over their right to life, of which they themselves had lost sight.

Those in the third category of chronically ill did visit the clinics and either went onto treatment or expressed a willingness to do so when the time came. However, they attempted to do all this secretly. Most tried to avoid the clinic nearest to Ithanga like the plague. It may have been 15 kilometres away, but local people came in and out and walked down the public road opposite the clinic, and people were aware that if they were seen, gossip would quickly make its way back to Ithanga. Most tried to enrol either at a clinic in Lusikisiki's town centre or in a village at the opposite end of Lusikisiki where nobody would recognise them.

As soon as they did this, they came up against one of the fundamental principles of the MSF ART programme: everybody received treatment at the clinic closest to his or her home. MSF's insistence on this principle was motivated in part by the belief discussed above, that making Aids and its treatment visible would reduce the stigma. However, something else was also at stake. Those who went for ART close to home, MSF argued, were far more likely to adhere to treatment. In local settings, health care providers know the names, homes, and circumstances of patients. If a person defaults, community health care workers will know where to find him or her.

Therefore, as a strict rule, MSF sent all those who sought the anonymity of a distant health care centre back to their local clinic. Many Ithanga people going onto treatment thus began living in a twilight zone. They would not disclose their status to neighbours and friends. When the time came for them to attend their weekly support group meetings or to keep an appointment with the clinic nurse, many would try to sneak out of the village and walk the full 15 kilometres to the clinic or take a taxi while pretending to be going to town.

However, frequent trips to the clinics could not possibly remain undetected and the fact that the people were on ARVs thus became an open secret in the village. Many people knew, but nobody would say. The entire epidemic and its treatment were covered in a cloak of discretion.

## TWILIGHT ZONE

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. Every villager

knew that many neighbours and friends were HIV-positive. The virus could be associated with particular names and faces. 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 be put on treatment. These are considerable achievements. A revolution in popular knowledge and understanding of Aids had occurred as a result of the arrival of the treatment programme. The lives of many villagers had been prolonged and the grief and economic hardship their deaths would have inflicted on their families had been averted.

What had certainly not been achieved, however, 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 the disease had shifted, had been displaced and had found new forms, but it was far from eradicated. The twilight zone in which those with Aids lived—their status known but seldom spoken of, their trips to the clinic noted and murmured about behind closed doors, the sight of their faces eliciting a polite greeting behind which dark thoughts were concealed—had become the entrenched reality of Aids in Ithanga.

The political dimension of this syndrome is discussed in next chapter.



# 4 Herbs and pills

In South Africa, the question of Aids is inseparable from the controversies that have raged about its causes and its treatment. President Thabo Mbeki's public questioning of the viral aetiology of Aids and his and his health minister's concerns about the toxicity of ART were for a time the dominant and abiding theme of national politics.<sup>9</sup> My Lusikisiki fieldwork suggests that, in opaque and indirect ways, their questions about Aids and its treatment reflect a powerful strain of racial resentment with deep roots in African communities. This theme deserves its own chapter, I believe, because such resentment is an obstacle to treatment and needs to be understood. I have chosen to illustrate this theme by telling one simple anecdote.

A few months after I had begun my research, I asked Sizwe whether I could employ him as an interpreter during my visits to Lusikisiki's clinics. He immediately agreed and confided that he had his own reasons for wanting to see the ART programme up close. There was illness in his family. His niece, to whom he was very close and for whom he felt responsible, had tested HIV-positive several months earlier. It was a secret only he and his mother knew. He felt it was up to him to help his niece decide what to do. Seeing the treatment programme would guide him in the choices he was to help her make.

We visited several of Lusikisiki's clinics over the following months. Whenever I asked Sizwe whether he would advise his niece to return to the clinic for a CD4 count, he gave an evasive answer. I soon stopped asking him.

For the duration of our time together, Sizwe insisted on taking me to traditional healers who were said to have a cure for Aids. He told me it was necessary for my research, and I agreed. However, he clearly had his own reasons. We tried to visit a young girl near Mthatha famous for her Aids remedy. When we arrived at her village, a queue of people some 200 metres long stretched from her homestead. We waited a long time. When dusk fell, we were told she that she was tired and would see no more people that day. We returned to Ithanga empty-handed.

We visited two other healers during the following months, but Sizwe appeared to be unimpressed with both of them and did not buy their medicines. Finally, at a funeral of a distant relative, we encountered a healer in whom Sizwe took a keen interest. He told me firmly that he wanted me to give the healer a lift home and for us to see his medicines.

In the car, I asked the healer, a young, shy man in his late twenties, about his cure. He said he had not been trained as an *iqqira*, a diviner-healer, but that, as in the case of *amagqira*, his work was guided by his ancestors.

'The ancestors started calling me when I was very young,' he said. 'It was the 1980s. I was a small boy. There was big fighting at that time. The young men's associations were fighting wars against one another. And then there were other people who were struggling against the government. The ancestors came in my dreams and told me to do this and this and this. I went as far as Natal to get *muti* for people to stop the bullets entering them.'

'What are the diseases you have learned to cure?' I asked.

'Any disease. If someone comes with an illness I cannot heal, I tell him to go. As soon as I go to sleep, all the ancestors come, even the ones I have not seen before.' He nodded in Sizwe's direction. 'This one's grandfather, who I never met in life, my grandfather introduced him to me in my dream.'

'How do you recognise Aids?'

'I need a card from the clinic. The patients must go to the clinic and come with the card saying they are HIV-positive. Then I give him two litres of medicines: they are herbs I have been told to fetch in my dreams. When the two litres is finished I tell them to go back and test again. The test will be negative. I don't reduce the Aids like the doctors. I kill the disease.' He paused a moment and

then added, 'I charge R200 for the two litres. But if the person doesn't have the money, I give the *muti* anyway, to save their life.'

'So many people have died from Aids,' I said. 'If the ancestors know how to cure it, why have they let so many people die?'

'The people only trust the doctors,' he said sorrowfully. 'They don't want traditional herbs. They trust Western doctors and they die.'

Sizwe bought a two-litre bottle of *muti* from the healer. It was a mixture of three types of herbs, all picked from his garden. That evening, Sizwe instructed his niece to take the medicine, refrain from sleeping with her boyfriend for two weeks and then go to the clinic and test again for HIV. She followed his instructions. At the clinic, her test was positive once again. This time, however, she also had her CD4 count taken. It was 435. She was perhaps as long as two years away from needing treatment.<sup>10</sup> She and Sizwe agreed that she would return to the clinic at three-month intervals to have her CD4 count taken and that when the time came, she would begin ART.

I was in Johannesburg when Sizwe's niece went for her test. On the telephone, Sizwe insisted on defending the healer's integrity.

'He did a very good job,' Sizwe said repeatedly. 'I am happy with him. If it were not for the herbs, my niece would never have gone to test, perhaps until she was dead. I am very happy with him. I must make a special trip to thank him.'

Some nine months later, Sizwe and I found ourselves driving past the healer's place. Neither of us had spoken of him in a long time. I nodded in the direction of his house.

'Have you seen him lately?' I asked.

'When you wrote about him in your book,' Sizwe replied, 'why did you say that the fence around his property was knee-high?'

I was in the process of writing a book about my journeys with Sizwe at the time and had shown him draft chapters as I worked.<sup>11</sup>

'I don't remember,' I replied. 'Did I say it was knee-high? Is it knee-high?'

'It is about the height of the stomach. You exaggerated. You wanted to show that the man's place was f-cked up. What fool wastes his time and money building a knee-high fence? Anything can get over it, even a small dog.'

He had said nothing of this when he had first read the chapter about the healer. That had been some six weeks earlier. It was one of those thoughts, I suppose, that one holds back. Now he was telling me he had seen his world

through my eyes, and what he saw was people with useless fences around their gardens and useless bottles of herbs in their rooms.

I recalled his defensiveness on the telephone when I asked him whether the healer's cure had worked, and I think I saw now what he was protesting against when he shielded the healer from me. He was protesting against a collective humiliation. Black people have fallen ill in droves and line up outside the clinic to obtain the medicine the white doctor, Hermann Reuter, has brought. It is humiliating. Before the gaze of their community, they are singled out as the bearers of a disgraceful disease; they must sit in support groups out in the open where they can be seen by passers-by, and they must steal off to the clinic in secret when it is time to see the nurse for fear that people will talk behind their backs. For the rest of their lives they must swallow ghastly pills that only serve to remind them that they are sick and that each cough or bout of diarrhoea could lead to death.

Sizwe wanted very much for an end to this situation. He wanted a cure, not a lifelong treatment he believed to be humiliating. Moreover, he desperately wanted the cure to be delivered by a dose of Mpondo medicine, a gift from the ancestors that heals one now and forever and puts paid to the queues outside the clinic and to the counsellors in the school hall.

I had repeatedly reminded him of the situation. I went to the healer's place, and what I saw was a knee-high fence. According to his interpretation, I had written that Mpondo cures were useless, that Sizwe's culture had been not only dominated and suppressed but also robbed of its wisdom. Black people were sick in droves and their only salvation lay in queuing up for a humiliating Western medicine.

I use this story as an exemplar of a large and pervasive theme, that of racial resentment. For all that his views changed on many issues during my research, Sizwe remained adamant at all times that HIV originated in Western laboratories. Almost everyone else in Ithanga I got to know well enough to ask acknowledged that he or she shared this belief or, at the very least, believed it to be a proposition that might be true. Thus both the existence of Aids and its treatment were understood to be a political and racial attack.<sup>12</sup>

Indeed, whether as shame or as witchcraft or as white conspiracy to murder, or as all three combined, Aids is experienced as an assault. Experiencing Aids as an assault is but a small step to experiencing Aids medicine as an assault: one feels as if each pill swallowed constitutes another victory for one's aggressors.

There is little question in my mind that Sizwe wanted to save his niece from going onto ARVs because they were a symbol of humiliation and of racial defeat.

In this respect, the lived experience of Aids in Ithanga closely resembles the infamous ‘denialist’ views of South African President Thabo Mbeki. Mbeki’s views are those of a middle-class intellectual and a world leader, and they are therefore incomparable in many respects with those of the inhabitants of a Pondoland village. However, the resemblance remains strong. Mbeki certainly does not say that Aids was invented in a laboratory, but he does argue that the prejudices of white scientists have blinded them to the fact that immune deficiency in Africa is caused primarily not by a virus but by the accumulated ills of colonialism and neo-colonialism. Orthodox Aids science, he argues, blames the epidemic on Africans’ proclivity for sex, when the real cause is poverty. In this sense, Aids science is indeed, for Mbeki, an attack on Africans, an attempt to stereotype and humiliate a people suffering from generations of powerlessness. Moreover, ARVs, he argues, herald a false dawn: they are toxic, and they do not prevent people from dying from immune deficiency.

There are no televisions and no newspapers in Ithanga. While most people I spoke to were firm supporters of Thabo Mbeki, few were well versed in his views on Aids. Yet I have no doubt that were Mbeki to spend an evening in the village and share his views, they would resonate deeply with those of many ordinary villagers.

ART programmes have perhaps not been sufficiently cognisant of this aspect of the meaning of ART. Few activists are comfortable acknowledging that the treatment they bring is experienced by some as a humiliation or an insult. Yet understanding the phenomena of pride, insult and recognition is crucial to designing successful ART programmes.



# 5 Service delivery

I have left until last arguably the most important factor shaping people's opinion of ART, whether they seek it, and whether it works: the quality of the health care service that provides ART. This investigation requires restarting at the beginning of the story and approaching the matter from another vantage point. Until now, the arrival of ART has been investigated from the perspective of an outlying Lusikisiki village. This chapter studies it from the vantage point of the clinics tasked with administering it. One needs to begin by supplying background information.

About a year after MSF launched its Lusikisiki programme, the South African government, which for years had prevaricated on the question of treatment, began a national ART rollout. The model it chose was hospital-based. In any given district, the hospital would be accredited to dispense ART. When hospital waiting lists grew, they could down-refer patients to the surrounding clinics.<sup>13</sup>

MSF believed that this model would fail to reach the majority of people in need of ART. The South African Aids epidemic was too extensive and shortages of medical personnel were too severe to restrict treatment to hospitals, the organisation said. Programmes would quickly bottleneck. The ill would either die waiting or they would not even bother to come.

To reach everyone in need of treatment, MSF argued, ART must be based on two principles. First, it must be as decentralised as possible. There are more than 3 000 primary health care clinics in South Africa, and they ought to be the primary sites at which ART is offered. Second, the scale of the South African epidemic is too large and medical personnel are too scarce for treatment to be doctor-led. The personnel at the forefront of providing ART ought to be nurses and laypeople. Nurses should be given the authority to initiate people into ART, and their workload ought to be alleviated by transferring such tasks as patient preparedness, follow-up and data collection and analysis to lay workers.

MSF's argument that the main burden of ART be placed on primary health care was controversial. Some argued that nurses and laypeople were unqualified to manage ART and that it required specialist medical expertise. Others argued that South Africa's primary health care system, particularly in rural areas, was too weak to withstand the burden of delivering ART: the system would either steal resources from other critical primary health care functions or it would collapse entirely under the strain. MSF's response was that if clinics were given the resources and the expertise to deliver to one critical health care service, their success would spill over into other spheres of work. After all, Aids medicine of necessity required dealing with a wide spectrum of chronic illnesses and required clinic managers to learn and master the public health techniques necessary to combat illness in general. In other words, giving clinics the responsibility of ART would invigorate, rather than destroy, the primary health care system.

The Lusikisiki programme thus established itself amid much controversy. Its response to its critics was emphatic. If ART is hospital-based and doctor-led, most people who need treatment will die. If people are made to travel long distances from their home and queue for hours on end and then be put on a long waiting list for treatment, they will stop coming. If, however, ART is available within walking distance of their homes and clinics are staffed by laypeople who know them and who will prepare them well for treatment, ART will be available to all and people will come to obtain it.

## **BUILDING THE TREATMENT PROGRAMME**

When MSF came to Lusikisiki, the primary health care system it intended to fight a great plague was profoundly unaware of the organisation's plans. Of



Lusikisiki's 12 clinics, two had a reliable electricity supply, one had running water and a telephone and none had a fax machine. Few of the medicines on South Africa's Essential Drug List had ever found their way to the district's clinic shelves, and those that had were there only sporadically. Most significant of all, perhaps, less than four in ten nursing posts were filled.

Per capita, the district had 14 times more people per doctor than the national average, and in that sense, MSF was surely right: either Lusikisiki's battered clinics and overworked staff would fight the epidemic, or no one would.

'During my first week here,' Hermann Reuter recalled, 'I went to each clinic. The nurses' first question: "Are you doctor?"'

"Yes, I am a doctor."

'Big welcome dance. First time they have seen a doctor coming to the clinic for five years. Lots of excitement. Until I start talking about HIV. They say no, they don't think HIV is a problem in the community. They don't treat anyone with HIV. *Ja*, they went to a funeral and someone said the person died of HIV, but we don't know.'

MSF's task was to renovate a vastly under-resourced system and to convince its depleted staff that the greatest epidemic in living memory was in their midst and that it was their job to treat it.

Within six months, the organisation had indeed built the clinics into institutions that could deliver ART. It did so by buttressing the system with laypeople and by using the time, commitment and growing medical knowledge of the ARV users themselves.

A cohort of adherence counsellors, recruited and trained by MSF and put on the organisation's payroll, did the lion's share of Aids work in the clinics. They performed voluntary counselling and testing, prepared patients for treatment, established support groups for antiretroviral users, monitored adherence and collected and collated data. They were as much community activists as health workers, visiting families who had thrown the HIV-positive out of their homes and staffing mobile testing units, such as the one that had so unnerved Sizwe in Ithanga.

MSF recruited six people as pharmacist assistants. Their task was to dispense medicines, monitor low stocks and place persistent and unrelenting pressure on the relevant bodies to supply the district's burgeoning need for medicines.

MSF also built a relationship with a nascent Lusikisiki branch of the Treatment Action Campaign (TAC). Its members worked among ARV users

in the clinic-based support groups, persuading users to trace treatment defaulters themselves, recruit others to test and give treatment a visible face in the villages.

The people MSF recruited were young and literate. They lived in a backwater town where career prospects were bleak and the course one's adult life might take uncertain. MSF gave them the prospect of a career, a new discourse with which to understand their lives and their town, and an ambitious project. They took to their work with voracious hunger, injecting unprecedented energy into the health system.

There can be little doubt that this grassroots, decentralised model had considerable success. According to the best-available actuarial model, between 100 and 110 people fall ill with Stage IV Aids in Lusikisiki every month. By the first quarter of 2006, three years after it had begun, the programme was putting over 100 people on treatment every month (MSF 2006:8–9). The rate of treatment had caught up with the rate of illness. That this was accomplished in a system that just three years earlier could not even secure a steady supply of essential medicines was an extraordinary feat.

Yet the very impressiveness of the project's accomplishments also pointed to the sources of its instabilities. When the programme began, about 60 per cent of nursing posts at Lusikisiki clinics were vacant. Three years later, when the programme was putting as many as 110 people on ART every month, the vacancy rate remained about 60 per cent. There were few reports of clinics turning people away or of people waiting to be put onto treatment. However, the system was under severe strain. Before the advent of the ART programme, a Lusikisiki clinic nurse saw an average of 27 patients a day. At the height of the programme, he or she was seeing 49 patients a day.

While MSF staff remained in Lusikisiki, the system would clearly cope. The organisation brought sufficient moral leadership, extra resources and the necessary managerial and medical expertise to keep an understaffed system functioning well. However, MSF's involvement in the project was always time-bound. The very point of its intervention was to show that ordinary primary health care institutions in poor settings could administer ART. In October 2006, the organisation left Lusikisiki. Much of the resources it had brought and many of the people it had trained were left behind and were integrated into the public health service. Nevertheless, a number of questions remained about the programme's stability after the organisation's departure.

All these matters related in one way or another to understaffing. First, over the past three years, a cohort of Lusikisiki nurses had been trained in Aids medicine. However, with vacancies unadvertised, a clinic nurse seeking promotion has to leave the Lusikisiki district. It is quite possible that the cohort of staff trained in Aids medicine will disappear in time to come.

Second, it is not clear whether the system, and nurses in particular, will continue to put up with the massive workload in the absence of MSF's charismatic leadership. Over time, nurses may well begin to ration their workloads in various ways. One would be to begin marginalising the young laypeople MSF trained and put in clinics. Nursing culture is deeply hierarchical, some would say quasi-militaristic.<sup>14</sup> The laypeople MSF recruited always occupied a somewhat precarious position in the clinics. One view was that the laypeople were alleviating nurses' workloads by performing VCT, patient preparedness, data collection and so forth. Another was that they were responsible for bringing too many patients into the clinic. It was possible that overworked nurses would try to relegate laypeople to the periphery of their clinics.

Another way in which clinic staff might ration workloads is by providing inadequate patient care or discouraging patients from reporting to clinics. I heard several reports of patients' being told that they had sun blisters and being given paracetamol when, in fact, they had shingles, a common opportunistic infection associated with Aids. Some ARV users were scolded and even threatened with being removed from the ART programme for coming to the clinic before their scheduled appointment, even though they did so because of chronic sickness.

A few months before MSF pulled out of Lusikisiki, the programme suffered an unexpected setback. In June 2006, the national health department began to enforce a stipulation, which had previously remained unenforced, that only doctors, and not nurses, could initiate ART. Since the Lusikisiki programme was nurse-led, this was a disaster. Unable to attract doctors to the bottom-rung posts it could offer, the clinics began 'borrowing' ward doctors from the regional hospital in Lusikisiki; they would come to the clinics twice a week to initiate patients into ART. It was hardly an optimal state of affairs.

My last fieldtrip to Lusikisiki was in February 2007, less than four months after MSF had left. The programme had faltered somewhat in late 2006. In October, it had recruited just over 50 people onto ART, less than half the monthly figure of the first half of the year. By February, however, the programme had staged an impressive recovery. Once again it was putting more than 100 people

a month on ART. Clinic personnel were adjusting to the absence of MSF and to the protocol of doctor-initiated treatment. Nurses and adherence counsellors had found creative and innovative ways to get patients and patient folders to the limited supply of doctors. There were, however, reports of severe system stress. Some clinics were not ordering drugs in time and their shelves stood empty. Several reports indicated that patients had been sent away when they had come to clinics before their scheduled appointments with complaints of illness. In one instance, ARVs were not dispatched to a remote clinic and users there defaulted on treatment. The overall picture was that of a system coping, but very imperfectly.

The greatest test, of course, was time. Much of the stress caused by personnel shortages would be felt over the coming months and years. Whether a clinic system can keep treating an epidemic with a 40 per cent nursing staff complement is an open question. One of the causes of these shortages is a national scarcity of nurses. However, that is only part of the story. In Lusikisiki, vacant posts were not advertised year in and year out. Therefore, the immediate problem was not a shortage of nurses to fill posts but a lack of budget. For this situation, MSF blamed the government's hospital-dominated ART rollout. In one district after another across South Africa, hospitals, not clinics, were accredited to administer antiretroviral treatment. Consequently, since it is the accredited site that receives the lion's share of new resources and posts, the prophecies of those who warn that clinics cannot administer treatment are self-fulfilling.

## **PERSONNEL SHORTAGE, TREATMENT-SEEKING BEHAVIOUR AND STIGMA**

The effects of staff shortages at health care institutions on health-seeking behaviour and stigma are complicated but powerful. It is a theme that is perhaps most adequately addressed in the form of a story.

Nomvalo is a village about 30 kilometres from Lusikisiki. With a population of between 500 and 600 people, Nomvalo finds itself just outside the MSF ARV programme's jurisdiction. Its local clinic, Ntafufu, does not provide ART. When the MSF programme began, Kate Marrandi, a community health worker in Nomvalo, heard of it. She began shepherding ill people the 30 kilometres to Village Clinic in the Lusikisiki town centre to put them on treatment. By the

time I met her in early 2006, she was responsible for putting more than two dozen people on treatment.

ART was thus located in a twilight zone in Nomvalo. Those on treatment generally did not talk about it publicly. Their relation to their treatment was mediated through their relationship with one woman. While their neighbours generally knew that they were on treatment, they did not speak freely about it.

It was this uncertain condition that Kate Marrandi wanted to change. In early 2006, she arranged with the NGO that employed her as a nurse to come to Nomvalo on a Saturday morning to perform VCT. She sought and acquired the permission of the local chief. Then she addressed every church group in the village, as well as the local high school. By the time testing day came, everyone in the village knew of it. Marrandi's plan was to gather all those who tested positive on testing day into a support group with people already on ARVs. Her idea was to transform HIV and its treatment into a public discourse and have it discussed openly and informatively throughout the village.

As in Ithanga a year earlier, testing was only ostensibly confidential. Many in the village gathered at the testing site and watched who went in and how long it took them to come out. By the end of the day, seven people, all of them women, were known by the community to have tested positive. Among them were two teenaged girls. Shocked and bewildered by the news they had just received, they approached Kate Marrandi and asked her what they should do.

Now, Marrandi had visited her local clinic, Ntafufu, a week earlier. The nurse in charge had told her that although the clinic still did not offer an ART service, it now had a facility to take CD4 counts. Consequently, Marrandi advised the two teenage girls to go to Ntafufu, have their blood tested and then report the test results to her.

'If I just knew the CD4 counts,' Marrandi told me, 'I could give them guidance. If their count was, say, 500, I could tell them it will be a while before they must start treatment, that they must have their blood tested again in three months, that they must eat well and exercise, and so forth. If their CD4 counts were already below 200, I would take them immediately to the clinic in Lusikisiki to prepare for treatment.'

The two girls reported to Ntafufu Clinic and asked to have their blood taken. They were told that the clinic did not handle matters related to HIV and they should go instead to Lusikisiki. They went back to Kate Marrandi and reported what had happened.

‘I was angry with the Ntafufu people,’ Marrandi told me, ‘because they had gone back on their word. I was forced now to send these two girls to St Elizabeth’s Hospital in Lusikisiki. But I made a mistake. I gave instructions in English. I said “CD4 count”, whereas I should have told them in isiXhosa. I should have said “*bala amajoni*”—“count your body’s soldiers.”’

‘They went to the hospital and by the time they got there they had forgotten these words “CD4 count”, so all they said to the nurses was, “We tested HIV-positive in Nomvalo; the community health worker there said we must come here.” And the nurse said to them, “You must go home and not come back until you get sick.”’

‘So now the two girls came back from the hospital empty-handed. They were very confused. They went to their church, a small Zionist sect that has a branch in Nomvalo, to share with their prophet what had happened to them. And at the church they were told that if they pray they will get better. God will make them better, not pills. That was when they began to deny that they were HIV-positive. Sent out by their church, they started to visit the ones who had tested HIV-positive the previous Saturday, and they said to them, “Do not believe that blood test. Come and pray and you will be okay.” And then they began to visit the ones who were on ARVs, and they said, “Our prophet has told us that it is God who will make you better, not these pills.”’

In the wake of the two girls’ period of activism, a tense and widespread public discussion about ART broke out in pockets around Nomvalo. For some time, participants in the debate seemed to be divided into two camps. Some said that the pills worked, evidenced by the fact that one villager after another had fallen ill, begun treatment and become better. Those who spoke against the pills retorted that the ARV takers were lying. The reason they were getting better was that they were secretly taking traditional medicines. Vicious rumours about the pills themselves began to circulate.

‘Some people are now claiming that the drugs are very dangerous,’ a Nomvalo woman who had been on ART more than a year told me. ‘They say that the big oval pill, the one that is shaped like a rugby ball and is hard to swallow, that one will make you give birth to a deformed baby. The baby will come out the same shape as the pill, without arms or legs. And they say that the pill that is a little red-and-white capsule with the powder inside, that one will make you mad. And the third pill, I forget now which one, they say it gives you epilepsy.’

The inversion is cruel. In the ARV support groups, each pill is handled and named and nicknamed and the associated side effects are learnt by heart. The coupling of detailed knowledge with familiarity is meant to strip the veil of mystery from the drugs, giving their users a measure of mastery over them. Here the idea of individualising the pills is mimicked, but only to underscore their treachery.

Kate Marrandi had been let down by the health care providers around her and particularly by the staff at Ntufufu Clinic. Her quest to bring the discussion of Aids in Nomvalo into the open had certainly succeeded, but her intent to take control of its public meanings had failed. Yet the damaging effects of the rumours about the pills and of the position advocated by the Zionist church should not be exaggerated. Most of those talking treacherously about ART in Nomvalo were healthy and were thus talking about others, not themselves. It is one matter to assume a position on Aids when one watches others from a distance; the gallery has never been a thoughtful or generous place. Falling ill oneself is another matter entirely; there is nothing like the emergency of one's own failing health to expel dogma and invite openness. MaMarrandi will still be there looking out for the sick. She will knock at their doors and sit in their living rooms and quietly explain the treatment process, and she will offer to accompany them to the clinic. How many will say no? Those who are uncertain are prone to experiment. Many will go with her, no matter what they are saying now. The critical question is whether the health system will treat them better than it treated the two teenaged girls who sought succour at their church.

Indeed, it was the two girls' nasty experience of the health system that appears to have triggered the flurry of rumours and accusations that followed in the wake of testing day. Had the nurses at Ntufufu taken their CD4 counts, they would have gone back to Kate Marrandi with the results and she would have been able to describe their situation to them in the form of a medical narrative. The next six months, one year, and then several years would have been mapped out for them. They would have been able to question those villagers on ARVs about their experiences of treatment. As it was, they were turned way from not one, but two health care institutions, and once that had happened, MaMarrandi was powerless. The medical process that gives her definition of Aids its meaning and its substance was no longer there to undergird her words. Consequently, having been let down by government health care institutions, the girls turned to the one grassroots institution that would not spurn them: the local branch

of a Christian cult, one that shuns allopathic medicine and utterly blurs the distinction between illness and health on the one hand and good and evil on the other.<sup>15</sup>

Why did the two young women from Nomvalo receive such shoddy treatment, first at Ntafufu Clinic and then at the HIV unit at St Elizabeth's Hospital? A full answer is beyond the scope of this monograph; it would involve both an institutional analysis of the health system and a detailed ethnography of what it means to be a nurse at a clinic in a former bantustan. For the purpose of this monograph, however, there is a fairly simple set of answers. First, Ntafufu Clinic was 60 per cent understaffed on the day the two Nomvalo girls walked through its doors. Second, the clinic had not advertised any of its vacant posts in several years, so the staff on duty knew that if patient numbers escalated, their workload would rise in equal measure.

When I relayed the Nomvalo story to Hermann Reuter, head of the MSF project in Lusikisiki, he smiled wryly. 'Your story is a classic symptom of understaffing,' he said. 'It's a variant of a very old story. Ntafufu Clinic is, I don't know, maybe 60 per cent understaffed. They've just made available a new service, CD4 counts. When an understaffed clinic has a new service, they get scared. They worry about overwork. And so when people ask for the new service, they say no, go to Lusikisiki. And at Lusikisiki, at the HIV unit at St Elizabeth's, maybe they were unfortunate enough to find a nurse who was also too overworked and thought no, I am tired of attending to patients from the Port St Johns area. They must go to their own hospital. Once people have visited a health care institution and have been turned away, they don't come back. The local institution that was best staffed and most receptive to Kate's two girls was the Zionist church, so that's where they stayed.'

## **STAFFING, INSTITUTIONS AND THE FUTURE OF THE MEANING OF AIDS**

This is perhaps the most appropriate place to end the main body of this monograph, for the image it paints portends what is probably the gravest danger to the future of ART in South Africa. In February 2007, the South African government released an encouragingly ambitious plan for ART. It is envisaged that by 2011, three-quarters of those in need of treatment will receive it. To achieve this massive scaling up, the health system is to follow the example set by MSF in



Lusikisiki. It is envisaged that 70 per cent of those beginning treatment will do so with nurses in clinics rather than with doctors in hospitals.

The news is most welcome. However, the aim will be achieved only if human resources and infrastructure are significantly injected into the clinic system. Budgetary reallocations must be made to advertise the immense number of nursing vacancies across the system. In addition, a system must be implemented across the country to redistribute the tasks traditionally associated with nurses to laypeople.

In the absence of these measures, stories such as the one from Nomvalo will characterise ART in villages, towns and cities all over South Africa. Clinics will provide ART, but nurses will ration their workloads by sending patients away, underutilising the services they are meant to offer and offering inferior treatment. Shunned by health care institutions, many people with Aids will turn to the vibrant world of traditional healers, lay healers, entrepreneurs, preachers and local prophets, who will receive them far more warmly than nurses. In the context of hostile clinic staff, many of these laypeople will establish themselves as competition to the health system, offering rival meanings of Aids and rival treatments.



## Appendix A

# HIV/Aids and sexual shame

Two abiding themes in the literature on the South African Aids epidemic and, indeed, on the epidemic generally are the connections between stigma and sexual shame on the one hand and stigma and witchcraft on the other. The two appendices bring the material I gathered during my fieldwork in Lusikisiki to each of these themes. The first appendix tackles a specific question in regard to the connection between stigma and sexual morality: the seeming capacity of the HIV virus to manufacture sexual shame where, apparently at any rate, none had existed before.

### **AIDS AND SEXUAL SHAME: THINKING THROUGH A PARADOX**

In an essay on Aids and witchcraft in South Africa, Adam Ashforth (2002) suggests that it is unlikely that sexual shame is a significant source of Aids stigma. There is, Ashforth writes,

... hardly a family in the country that does not have unmarried daughters giving birth to children, sons being sought to support their offspring,

or fathers finding long lost progeny they secretly sired many years back. Sexual misdemeanours are shameful but commonplace. And while the disease was first registered in South Africa amongst white homosexuals, nobody identifies it now as a 'gay disease' or stigmatises its victims for their sexual orientation.

The stigma associated with Aids, Ashforth (2002:135) continues, makes more sense when its witchcraft dimensions are considered:

With cases of witchcraft, silence and discretion are the norm. No-one wants to publicise the fact that they have been cursed. Such publicity would not only be embarrassing, but dangerous, because it would enable the witch to gain intelligence of the efforts being made to counteract his or her occult assault.

One can understand Ashforth's reasoning. He is right to point out that while 'sexual misdemeanours' might be shameful, they are also commonplace. How, then, can they possibly constitute a significant source of Aids stigma?

The problem is that they patently do. When asked whether contracting Aids was shameful, the vast majority of Lusikisiki informants said yes. Asked why, they said that the shamed one had been sleeping around and had thus brought a deadly disease back to loved ones. It was not a question of taking a tactical decision to keep one's affliction secret in order to put up a better fight against the witchcraft that caused it. It was, simply and nakedly, a matter of sexual shame.

The question can thus be restated as a paradox. Why do 'sexual misdemeanours', to use Ashforth's phrase, attract mild shame and gentle opprobrium when the person in question remains healthy, but violent and mortifying shame when he or she falls ill with Aids? Clearly, the presence of the virus dramatically recalibrates the relationship between sexual activity and moral censure. How and why does it do so? Why does the disease turn commonplace disapproval into a murderous accusation?

## PARADOX IN LUSIKISIKI

When one reads literature on the history of twentieth century sexual morality in Pondoland, one is struck particularly by the paradox. Historically, Mpondo

attitudes to sexuality and particularly to multiple sexual partners have always been sophisticated, pragmatic and quite permissive.

When the anthropologist Monica Hunter did fieldwork in Pondoland in the early 1930s, she noted that ‘very many married women have lovers, whom they meet secretly when going to fetch wood or water, or coming back from the fields, or after social functions. ‘In “affairs,”’ Hunter writes, ‘women stand by one another in a sexual group, a woman’s co-wife, sister-in-law, or even her mother-in-law, often acting as go-between with a lover.’

Indeed, she remarks, ‘it seems to be no disgrace for a woman to commit adultery—the more skulls the better—and the only preventive lies in the danger of being caught by her husband and beaten. Adultery is no grounds for divorce. If a husband sends home a wife for that alone he forfeits his *ikhazi* [bridewealth]’ (Hunter 1961:203).

Hunter also comments with barely concealed admiration on the sexual and economic independence of divorced women, *amadikazi*. They return to their parents’ homestead where ‘they have less work to do and much greater freedom than wives’, and it is expected that they will take lovers to their huts, most of whom are married men. ‘Many [women] who dislike the labour and restrictions of a wife’, Hunter comments, ‘refuse to stay at any homestead to which they are taken as a wife, and run home to live as *amadikazi*’ (Hunter 1961:208).<sup>16</sup>

Sexual practices in Pondoland have of course changed considerably in the intervening seven decades. The institution of marriage and the productive peasant households that sustained it have been in decline for some time now. The spectacle of a woman’s mother-in-law acting as a go-between with her lover is not nearly as common as it apparently was when Hunter visited nor, indeed, is the *idikazi* who resides in her father’s homestead and entertains her lovers in her hut. However, although sexual practice has changed a great deal, the culture is still as tolerant of discreet serial and multiple partnerships as it was in the 1930s.

Most young Mpondo women today need to earn a living out of wedlock. Most cannot do that in their home village. Many thus make pilgrimages to cities early in life, sometimes as early as their mid-teens, and often alone. Although the formal reason for their travels is the search for work, it is implicitly understood that they will not be chaste after their departure from home and, indeed, that the line between finding work and finding a male provider may be a very

thin one.<sup>17</sup> Countless women embark on such journeys, and when they come back, they are not scorned or shamed.

Yet if a woman comes back from the city sick with Aids, her family is scandalised and she herself is in a state of unspeakable disgrace. A niece of Sizwe's, for instance, tested HIV-positive in 2005. It is a secret known only to Sizwe, his mother, and one other. 'I have to admit', Sizwe said reluctantly, 'that she went to Durban when she was 16 and the family does not know what she was doing there. Clearly she misbehaved herself and came home with Aids.' Furthermore, according to his mother, 'People must never know about this because it is too shameful. She went to the city, and look what she has done there. She has brought home this terrible sickness from the Zulu men in Durban.'

Yet if she had come home healthy, everyone would still have had a fairly good idea that she had slept with Zulu men and the knowledge would have cast no aspersions on her character. What changes once a person is infected with HIV? Why does the virus turn a sophisticated sexual morality into a parody of Victorian intolerance?

One answer that provides food for thought was given by a 60-year-old Ithanga informant. I will call her MaMgudu. I initiated a conversation with MaMgudu by giving an example of the paradox currently under discussion. I did so by taking an anecdote from Monica Hunter's book.

'There was a white woman here in Lusikisiki in the early 1930s', I said to MaMgudu, 'who wrote a book about Mpondo culture. At some stage during her research, she asked an Mpondo woman what she thought of Christianity. The woman laughed. She said the religion of the whites says married people must be monogamous. The whites are lying. It is no more possible for them to be monogamous than it is for us.'

My translator began to relay the story, and before he had finished, MaMgudu had begun chuckling to herself.

'What that white woman was told is right,' she smiled.

'But then I am confused,' I said. 'When I ask why having HIV is a disgrace, you say it is because the one who is sick has been sleeping around. And yet you have just agreed that it is no disgrace to fail to be monogamous.'

She listened carefully, and then thought for a long while.

'The confusion is about these sicknesses,' she said finally. 'These new sicknesses. Not so long ago, a wife could have a lover on the side. All that would

let the husband know was if she fell pregnant. It was difficult for a woman to be caught. It was easy to hide from the husband. Now with this disease, you can tell.'

What MaMgudu had articulated in enviably concise form was an account of Aids stigma recently developed by the sociologist Deborah Posel. Posel argues that the scandal unleashed by HIV is not so much about sex per se; it is rather that the epidemic has unveiled sex, robbing it of the discretion and the secrecy that always sheltered it.

This is one component of a larger argument Posel has made in a series of papers about the politics of sex in post-apartheid South Africa. She argues that the transition from apartheid to democracy has seen a parallel transition of sex as a matter located firmly in the private sphere to an explosively public and political issue. The manifestations of this transition are various: the birth of a post-apartheid youth culture that valorises consumption and sexuality as expressions of political freedom; the absorption of human rights discourse, including the rights to sexual expression and against sexual violation, into the fabric of South African culture; and, not least, the ubiquity of discourse about Aids, which has invaded the sphere of sexual intimacy not long ago considered a private sphere, with a host of public and political ideas ranging from autonomy and responsibility to violation, disease and danger.<sup>18</sup>

In this reading of the matter, sexual adventure, and particularly the sexual desire that is given expression in the course of sexual adventure, is permissible so long as it remains sheltered by discretion. Modes of discretion take form in an intricate filigree of practices of looking away. Once one is searching for such practices, they are evident everywhere.

In her early 1930s ethnography, for instance, Hunter observes that 'for a girl to elope is very shameful, for a girl should never admit that she goes willingly to any man. Always when she is married she should weep and protest; not to do so is immodest' (Hunter 1961:188).

This averting of the eyes from sexual desire was also readily apparent during my fieldwork seven decades later, not least during a conversation Sizwe and I once had about one of his younger sisters. Sizwe mentioned that when she was 16 or 17, his father would beat her for her sexual indiscretions.

'She was a very, very naughty girl,' Sizwe said. 'Every night, she was out. And she was stupid. She would come home from her boyfriend late, maybe six in the morning, when the whole homestead was up and about. If she had come home

at two or three in the morning, while her parents were asleep, there would have been no problem.’

It is not that the girl went out that offends; it is the spectacle of her return.

According to this reading, the accusation that fuels shame—that of excessive sexual desire, or of sexual gluttony—long preceded the advent of the Aids epidemic. It was always there, but it was always masked by layers of euphemism and silence. Aids tears these layers of discretion away. It does so by virtue of the fact that it is deadly, it is sexually transmitted, and it is killing large numbers of people. It both unmasks and enflames a sense of disgrace that was previously managed with great care. That the logic of the accusation against the infected is circular in no way reduces its power. The circularity of the accusation is approximately the following: What you have done is shameful because it is deadly. And the reason it is deadly is that it is shameful.

The force and the sheer wildness of these accusations are both extraordinary and extremely upsetting to witness, especially when they are levelled by loved ones. During the course of my fieldwork, I spent some time with two young women whose HIV-positive statuses were known only to select members of their respective families. I interviewed the mother of one of these girls several times. During the course of most of these interviews, she expressed only worry and pain. Yet at one point her grief gave way to an outburst of anger. ‘In my day,’ she said, ‘the teenage girls looked after each other. If one was going to have sexual intercourse with her boyfriend, the others would stop her, they would discipline her. The girls kept one another virgins right through their teenage years. Today’s girls are sexually greedy. They want, they want, they want. My daughter is sick now because she is a girl who knows no shame. She went away to find work, but look at the work she found. Behind our backs she was *isifebe* [a slut].’



## Appendix B

# Aids, witchcraft and the destruction of community

There is a small but very interesting body of work that has begun to theorise the relationship between Aids, witchcraft and the dissipation of social solidarity in post-apartheid South Africa. It is to this question that we now turn.

The most distinctive social change wrought on black South African communities since the end of apartheid, the argument goes, is a dramatic increase in inequality. To put the matter differently, there has been a collective race for the acquisition of a very limited stock of goods, and the ensuing relationships that have emerged between winners and losers are inherently unstable and often poisonous.

In the high apartheid era, inequality among black South Africans certainly existed, but it was contained at both ends of the spectrum. Racial discrimination put a low cap both on the black middle class's capacity to accumulate wealth and on its consumptive aspirations and opportunities. Middle-class people in urban townships lived in state-leased houses, like everyone else, had no access to expensive private health care, and faced limited choices in regard to their children's education. At the other end of the spectrum, wages may have been low but unskilled jobs in South Africa's industrial centres were plentiful and those who accessed them generally also accessed decent urban infrastructure: a home with electricity and water-borne sewerage.

Today, the caps at both ends of this spectrum have fallen away. Unemployment levels are considerably higher than they were in the high apartheid era and access to decent urban infrastructure is far less certain. The prospect of spending the first one, two or even three decades of one's adult life without a steady job, a regular source of income, or a home of one's own has grown enormously.

At the same time, the middle class has grown massively. Its identity is measured far more starkly than that of its high apartheid forebear by the need to accumulate material acquisitions: a good home in a decent suburb, expensive education for the children, and top-of-the-range medical care. The result twofold. First, the social distance between the middle class and the other ones grows; second, for those who aspire to membership of the middle class, the retention of a middle-class lifestyle becomes a strenuous financial burden.

These divergences in the fortunes of people take shape in intimate, face-to-face environments: on streets and in villages where the same families have been neighbours for generations, and within the families themselves. Consequently, intolerable strain is placed on norms of mutual reciprocity. Adam Ashforth (2005:28) expresses the situation best in his Soweto ethnography. He writes the following:

Although there are deeply rooted norms of sharing and reciprocity within families and communities, these function best when capacities for giving are relatively evenly distributed. When one person's needs today might be another's tomorrow, it makes sense to share and share alike. ... But when some people's needs are permanent and their capacities for reciprocity limited, habits and ethics of sharing come under strain.

Somewhat later, Asforth (2005:32) writes:

If a person with money in a family or network of reciprocity makes a major purchase, or even if she begins to enjoy a manifestly better standard of living than the rest, such as by wearing expensive clothes or moving out of the family home to a place of her own, then it is in a sense true to say that she benefits at the expense of others in something like a zero-sum fashion. Her gain is the others' loss. Moreover, since only a minority of people are earning income, for most people their standard of living depends upon having access to people willing to share.

Under such conditions, Ashforth (2005:32) argues, 'sharing and redistribution ... can engender complex relations of power and domination that breed resentments. Among these resentments is the jealousy that is said to give rise to witchcraft.'

In this scheme of things, the very structure of post-apartheid communities renders them acutely sensitive to suspicions and accusations of witchcraft. Into this environment comes the Aids epidemic, which kills young and middle-aged people in large numbers. Moreover, the ailments suffered by the epidemic's victims overlap considerably with a host of illnesses traditionally associated with witchcraft. It is thus by no means inconceivable, Ashforth argues, that the Aids epidemic comes to be understood among ordinary people across the country as an epidemic of murder among relatives and neighbours.

Nowhere is this grim vision more apparent than in Fred Golooba-Mutebi's ethnography of a Bushbuckridge village he calls 'Tiko'. The village is divided into two sections. One is inhabited by a group of Mozambicans who fled to South Africa during the civil war of the 1980s. The other is home to their hosts, a community of South African Tsonga speakers who have lived in Tiko ever since the apartheid resettlement schemes forcibly removed them from their land.

Members of the Mozambican community are more or less equal in their poverty. Most eke out a living doing seasonal farm work or domestic work for their South African neighbours; they work as taxi drivers or survive through remittances from relatives who work in the city. Levels of mutual reciprocity are extremely strong and rank very high among the survival strategies of refugees. While members of the Mozambican community believe in witchcraft as a matter of course, few think that the incidence of witchcraft in their village is high.

Members of the South African community next door are far less equal. The genesis of this inequality is less than a generation old. In the mid 1990s, several young, well-off members of the South African community, people with good jobs in the city, fell ill and died. It was widely assumed among their families and neighbours that they had been bewitched by envious villagers.

Today, Golooba-Mutebi writes, old bonds of social solidarity in the South African section of the village are threadbare. He marks this decline in sociability, among others, in the abandonment of a generations-long ritual of communal 'marula' beer drinking every February and March. Golooba-Mutebi (2004:11) writes:

In the past it was during this period that collective drinking would be at its height, as people invited each other to share beer brewed by their wives or mothers-in-law. Men used to gather in large groups to drink and talk to each other. These days, people drink alone or with kin and trusted neighbours and friends, sometimes in pairs.

In the refugee section of the village, in contrast, a great deal of 'collective drinking and merrymaking [takes] place among the residents themselves and with refugees from settlements in other villages in the area. Other refugees come to Maputo-sikomu [the Mozambican section of Tiko] and those from Maputo-sikomu go to other settlements to drink and socialise (Golooba-Mutebi 2004:12).

In the South African section of the village, it has become unusual for people to leave their children with neighbours or to accept food that was cooked out of sight or to seek help during hard times. As one of Golooba-Mutebi's informants says of her neighbours,

They see you drinking tea in the morning, and they start: 'look at that one drinking tea. Where did she get the money from?' It is as if they don't see me collecting scrap metal for sale. And when I have sold it, I come back with money, with sugar, tea and soap, so my children can look clean like those others. What do they expect? But they don't trust me. They say 'no, this woman must have a baboon that she uses to steal money from other people'. But I have no baboon. That's why we kill each other; it's because of money. That's why we hate each other. That's why we talk about witchcraft. (Golooba-Muteb 2004:11)<sup>19</sup>

## WITCHCRAFT AND AIDS IN ITHANGA

To what extent was this dark vision evident in Ithanga? Certainly, people expressed a great deal of anxiety in regard to the relationship between Aids, envy and witchcraft. When I met Sizwe, he was a fledging businessman, owner of a nine-month-old spaza shop and tavern. By the time we got to know one another, it was clear that his business was doing very well. On the day I met him, Sizwe told me that he did not think he could both be a successful businessman and live in Ithanga.

‘Where you are known,’ he said, ‘you cannot run a business. People see you through your parents and your grandparents and they judge you. They ask how a man can be successful when his parents are poor.’

‘What precisely are you afraid of?’

‘There have been things happening in my sleep,’ he said. ‘Twice now, I have woken up in the morning and I have been wet and sticky. I am 29. Wet dreams are for boys, for when you are maybe 13 or 14. I have Nwabisa sleeping next to me. I am a man.’

‘So what is happening to you when you sleep?’

‘Some people have maybe sent a demon to have sex with me: a demon with HIV. That is why I am scared to test. I think I will test positive.’

Yet when I asked Sizwe whether there had been a surge in witchcraft in recent years, he said no. So did every other young Ithangan I spoke to. When I asked them whether people trusted one another less today than during their parents’ times, most replied that in their parents’ day the greatest danger was witchcraft; today the greatest danger is violent crime.

I often pushed young people on this question. I summarised Ashforth’s argument and painted the picture of Tiko that Golooba-Mutebi had described. Generally, young people responded with indignation. ‘There is only one way to get Aids,’ was a standard response. ‘It is bad enough that so many people are dying. To say that they are actually being killed by jealousy makes it much, much worse.’

Perhaps the idea that an epidemic of envy is killing the young and the healthy in large numbers is indeed intolerable. Maybe people are eager to separate Aids from witchcraft in order to protect themselves from the idea that neighbours and family are murdering one another in droves. Perhaps people in Lusikisiki are protecting themselves from the intolerable fate Golooba-Mutebi describes. If Aids is indeed an epidemic of neighbourly hostility, the villages have descended into little more than a state of nature, one in which each soul lives in a cocoon of suspicion. Perhaps it is a need to preserve a modicum of solidarity that distances Aids from witchcraft.

The radical dissipation of social trust of which both Ashforth and Golooba-Mutebi speak is undoubtedly a latent possibility not far below the surface of the Lusikisiki landscape. However, it does seem to be a possibility against which people collectively guard, at some times more successfully than at others. Indeed, that Aids has so many alternative meanings and that the accusations

it hurls have as objects so many alternative culprits are perhaps mechanisms through which ultimate blame is forever deferred.

Indeed, through the course of this monograph three different forms of accusation levelled at three different types of culprits have emerged. First, the culprit is the infected person herself. She is guilty of contracting a virus through her promiscuity and then infecting people close to her. Second, the culprit is a person who envies the sick one and who has sent a demon to her to infect her with the virus. Third, the culprit is a racial and political conspiracy: the virus was invented in a Western laboratory outside or perhaps within South African borders and is being used as an instrument to decimate the country's black population.

To a greater or lesser extent, these three categories of accusation find themselves competing with one another. It is of course logically possible for all three to be true at the same time. The notion that Aids was invented in a laboratory does not preclude local witches from using it to kill those they envy, nor does it blunt the accusation that a person has killed loved ones through her promiscuity. Nonetheless, if one listens closely to the manner in which these three forms of accusation are used in everyday discourse, it does appear that they function to offset one another. Each overdetermines and limits the meaning of the other. Thus the idea that Aids was invented in a laboratory serves to protect a community from the idea that witchcraft is causing it to implode upon itself. In turn, the idea that Aids is transmitted through witchcraft is wielded to protect particular individuals from the shame of having contracted the virus. Each form of accusation is used to mitigate the sharpness of the others.

It is extremely important, I would argue, to locate the connection between Aids and witchcraft within this field of wider accusations. If the question of witchcraft is abstracted from this broader field, it is likely that one will misunderstand its social functions and its consequences.

# Notes

- 1 This monograph is the smaller of two research outputs following an eighteen-month research project on the meanings of antiretroviral treatment in Lusikisiki in the old Transkei. The larger companion to this monograph is a book published in February 2008 with different titles in South Africa and the United States. In South Africa the book is published as follows: Steinberg, J 2008. *Three-letter plague: a young man's journey through a great epidemic*. Johannesburg: Jonathan Ball. In the United States: Steinberg, J 2008. *Sizwe's test: a young man's journey through f Africa's Aids epidemic*. New York: Simon and Schuster.
- 2 The most sustained and cogent defender of this position is Paul Farmer. See Farmer, P 1992. *Aids and accusation: Haiti and the geography of blame*. Berkeley: University of California Press; Farmer, P 2001. *Infections and inequalities: the modern plagues*. 2<sup>nd</sup> ed. Berkeley: University of California Press; Farmer, P 2005. *Pathologies of power: health, human rights, and the new war on the poor*. 2<sup>nd</sup> ed. Berkeley: University of California Press. See also Kidder, T 2003. *Mountains beyond mountains: the quest of Dr Paul Farmer, a man who would cure the world*. New York: Random House.
- 3 Although he does not argue so explicitly, implicit in some of Adam Ashforth's work on witchcraft, stigma and Aids is the notion that ART will do little to erase the symbolic pollution attached to those considered terminally ill and thus do little to alleviate stigma. See, especially, the following: Ashforth, A 2005. *Witchcraft, violence and democracy in the New South Africa*. Chicago and London: Chicago University Press. For a more considered meditation on these matters, see Ashforth, A and Natrass, N 2006. Ambiguities of 'culture' and the antiretroviral rollout in South Africa. Working paper 156, April. Cape Town: Centre for Social Science Research. For an extended meditation of stigma and ART, see Cameron, E 2005. *Witness to Aids*. Cape Town: Tafelberg.
- 4 Ithanga is situated in Eastern Pondoland. While I am not aware of any scholarly studies of Ithanga specifically, Pondoland has been the subject of much scholarship. On the migration from Mpondo mines to the gold mines see Moodie, D 1994. *Going for gold: men, mines and migration*. Johannesburg and Berkeley: University of California Press and Wits University Press. The most accomplished and prolific social and economic historian of Pondoland is William Beinart. See, inter alia, Beinart, W 1982. *The political economy of Pondoland 1860–1930*. Cambridge: Cambridge University Press; Beinart, W 1986. *Pig killings, contagion and*

- purification in South Africa*. Paper prepared for Conference on Culture and Consciousness in Southern and Central Africa, Manchester; Beinart, W 1987. Worker consciousness, ethnic particularism and nationalism: the experiences of a South African migrant, 1930–1960. In Marks, S and Trapido, S (eds) 1987. *The politics of race, class and nationalism in twentieth century South Africa*. London and New York: Longman, pp 286–309; Beinart, W 1991. The origins of the *Indlavini*: male associations and migrant labour in the Transkei. In Spiegel, AD and McAllister, PA (eds) 1991. *Tradition and transition in South Africa: festschrift for Philip and Iona Mayer*. Johannesburg: Witwatersrand University Press, pp 103–128; Beinart, W 1992. Transkeian smallholders and agrarian reform. *Journal of Southern African Studies*, 11(2):178–199; Beinart, W 2002. Environmental origins of the Pondoland revolt. In Dowers, S, Edgecombe, R and Guest, B (eds) 2002. *South Africa's environmental history: cases and comparisons*. Cape Town: David Philip, pp 76–89. For a brilliant ethnography of Pondoland in the early 1930s, see Hunter, M 1961. *Reaction to conquest: effects of contact with Europeans on the Pondo of South Africa*. London: Oxford University Press (first published in 1936).
- 5 For a complete list of the forms of witchcraft and sorcery in Mpondo culture see Hunter, M 1961. *Reaction to conquest: effects of contact with Europeans on the Pondo of South Africa*. London: Oxford University Press, pp 272–319.
  - 6 For a recent bibliographic survey on shame, see Scheff, TJ (nd). Shame and the social bond: a sociological theory. Available at <http://www.soc.ucsb.edu/faculty/scheff/2.html> [accessed March 2007]. For a famous psychoanalytic statement on envy, see Klein, M 1963. Envy and gratitude. In Klein, M (ed), *Envy and gratitude and other works, 1946–1963*. London: Hogarth, 1975, pp 176–235.
  - 7 See Post, FA, Wood, R and Maartens, G 1996. CD4 and total lymphocyte counts as predictors of HIV disease progression. *QJM* 89(7):505–508.
  - 8 See, inter alia, Kapp, C 2004. Antiretrovirals give new hope and new life to South Africans. *Lancet*, 263:1710; Boulle, A, Coetzee, D and Darder, M 2004. Reflections and new challenges after four years of HIV services in Khayelitsha. *South African Journal of HIV Medicine*, 15:22–24.
  - 9 A great deal has been written on Mbeki and Aids, but the works of two writers tower above the rest. See Gevisser, M 2007. *Thabo Mbeki: the dream deferred*. Johannesburg: Jonathan Ball, Chapter 41; and Fassin, D 2007. *When bodies remember: experiences and politics of Aids in South Africa*. Berkeley, CA: University of California Press.
  - 10 Patients in the South African public health service begin ART when their CD4 count drops to below 200. At the time of writing, MSF was considering lobbying to have patients begin ART at a CD4 count of 300. Hospital care in rural districts such as Lusikisiki was poor, MSF argued. As a result, the people were dying of opportunistic infections shortly before or after beginning treatment. The infections would be easily treatable in better-serviced city environments. Starting ART earlier in rural settings, the NGO argued, would decrease mortality rates substantially.



- 11 See Endnote 1 above.
- 12 As the anthropologist Didier Fassin argues, in the phenomenology of everyday experience, Aids is understood through the filter of a long history of oppression. See Fassin, D 2007. *When bodies remember: experiences and politics of Aids in South Africa*. Berkeley, CA: University of California Press, pp 121–172.
- 13 For an account of the politics and practice of ART in South Africa, see Natrass, N 2007. *Mortal combat: Aids denialism and the struggle for antiretrovirals in South Africa*. Durban: University of KwZuluNatal Press.
- 14 On the politics and culture of South Africa's nursing professionals until 1990, see Marks, S 1994. *Divided sisterhood: race, class and gender in the South African nursing profession*. New York: St Martins Press.
- 15 On the Christian Zionist movement in South Africa, see Bengt Sundkler's classic study: Sundkler, B 1948. *Bantu prophets in South Africa*. London: Lutterworth.
- 16 For a unique survey and commentary of and commentary on historical and anthropological research on sexual morality, see the following series of three articles by Peter Delius and Clive Glaser: Delius, P and Glaser, C 2005. Sex, disease and stigma in South Africa: historical perspectives. *African Journal of Aids Research*, 4(1):29–36; Delius, P and Glaser, C 2004. The myths of polygamy: a history of extra-marital and multiple-partnership sex in South Africa. *South African Historical Journal*, 50:84–114; Delius, P and Glaser, C 2002. Sexual socialisation in South Africa: a historical perspective. *African Studies*, 61(1):27–54.
- 17 On the relationship between female migration, sex and livelihoods in contemporary South Africa, the work of Mark Hunter is unparalleled. See, inter alia, Hunter, M (forthcoming) Zulu-speaking men and changing households: from providers within marriage to providers outside of marriage. In B Carton, J Laband and J Sithole (eds), *Being Zulu: contesting identities past and present*. London and Pietermaritzburg: Hurst and University of KwaZulu-Natal Press, forthcoming; Hunter, M (nd). *Informal settlements as spaces of health inequality: the changing economic and spatial roots of the Aids pandemic, from apartheid to neoliberalism*. Research report 44. Durban: University Of KwaZulu-Natal, Centre for Civil Society; Hunter, M 2002. The materiality of everyday sex: thinking beyond 'prostitution'. *African Studies*, 61(1):99–120.
- 18 See Posel, D 2005. 'Baby rape': unmaking secrets of sexual violence in post-apartheid South Africa. In Reid, G and Walker (eds), *Men behaving differently: South African men since 1994*. Cape Town: Double Storey, pp 24–63; Posel, D 2004. *Sex, death and embodiment: reflections on the stigma of Aids in Agincourt, South Africa*. Paper for symposium on Life and Death in a Time of Aids, the Southern African Experience, WISER, 14 to 16 October 2004; Posel, D 2004. 'Getting the nation talking about sex': reflections on the politics of sexuality and 'nation-building' in post-apartheid South Africa. *Agenda*, December.
- 19 Extraordinarily, Golooba-Mutebi does not mention Aids once in his paper, even though it is clear from his account that the increasing rate of death among young and successful people has been pivotal in the rise in social estrangement.



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