



REPORTING
AIDS

What can we do now?

The nurse pointed at the long funeral procession coming down the slopes of the Drakensberg. “We are dying,” she said. For the last 30 years Mme Makaoe had been riding up into the highlands on her Basotho pony, to treat the sick. The villagers trusted her, she had grown up with them, they wanted her to be the one who tested them for HIV. I had arrived in a Piper Cub, writes *Henk Rossouw*, landing in a fallow maize patch, the only way to reach the village when the Senqu River was high. That night, Mme Makaoe sat me down in a stone house,

and, in the figurative language she used to explain things to the people of the mountains, she talked me through the hard science of CD4 counts, viral loads, how HIV causes Aids.

Six thousand feet above sea level, it became my moment of truth. As a journalist, Aids stories had been part of my routine but not part of my conscience. I knew the clichés about Aids but not how it felt:

Mme Makaoe routinely had to watch her patients die without antiretroviral treatment. That night, I couldn't claim ignorance anymore. "We are dying," she had said.

Only on my return to Jo'burg, where ARV treatment is commonplace – though not common enough – did I realise what Mme Makaoe meant.

Listen to her pronoun: "We are dying." She didn't have HIV but she included herself and myself and you – the audience, in her sense of "we". A death because of Aids, a treatable disease, is a loss for every member of the body politic, from the Union Buildings all the way down to Mathibestad, 70km to the north of Pretoria, population 21 700.

Mme Makaoe died a few days later, a taxi accident. This is in her memory. With the assistance of the Ruth First Trust and Wits University, I spent the winter of 2005 reporting in Mathibestad, a small town rife with Aids, in the fiscal shadow of the metropolis.

There are three pervasive things in Mathibestad: Dust, wood smoke, and generosity to strangers. In a town of massive unemployment, where some families of eight survive on a single child grant of R180 a month, I was often fed. Outside homes of corrugated iron there's always a couple of chairs under a tree for visitors to pass the time of day.

As subjects, even during times of grief and despair, the people of Mathibestad accepted my motives. I am a journalist. In turn, they wanted to be heard – loudly, clearly, honestly.

If the trust I gained seems automatic it's because they had first met me at the town's clinic. It's an anomaly within the health system. Three years ago, Dr David Cameron from the University of Pretoria converted the abandoned storerooms belonging to the adjacent public health centre into a new clinic. For the first time, other than nurses, the town had a regular doctor. Consultations are free; in exchange his students on rotation get to practise rural medicine.

In any society, healthcare is a barometer. To take an accurate reading, I sat in on dozens of consultations over the months. One patient skipped pills because the instructions on the packet said they must be taken after food and she had none; a household came down with tuberculosis because they lived in one room; another patient had facial bruises. The HIV epidemic is both the cause and the consequence of more hunger, more coughing, more bruises. These are the symptoms of South Africa's ills, the shrapnel of apartheid.

There's no glory in rural medicine. Doctors who leave medical school feeling omnipotent, who go into rural practice with ambitions of sainthood, quickly become disillusioned.

Giving patients what they really want is unsettling. I'm not talking about administering blood tests or filling out disability grant forms but a far deeper need: to be understood. There's no pill for that.

Often diagnoses are unclear – how to explain bodily pain that has no definable cause? Doctors raised on X-rays, MRIs, CAT scans, the tools of the city hospital, struggle to accept this uncertainty and then make a decision anyway. And you'd be surprised how many patients come to see the doctor with make-believe symptoms, in order to talk.

Truly listening to patients can be harder than surgery. Meanwhile, North West Province, where Mathibestad falls, has the lowest number of doctors



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in the country. The health department has raised the salaries of rural doctors higher than in the city but district hospitals remain bereft of staff.

In the age of medical aid's fifteen minutes or less, it's astounding that, at a clinic where patient's cannot pay, consultations may last for an hour, or however long it may take for a patient to tell their story.

The same principle applies in journalism. The truth – whether a truer diagnosis or truer reporting – needs time.

The Mathibestad clinic is a necessary luxury and a fellowship like the Ruth First is too rare. South African journalists need to have far more time to invest into their stories, especially when the agenda is this urgent. Spending enough time with people with HIV earns their trust and that bond is priceless.

By conventional standards of journalism, I wasted a lot of time. But if I had not sat through many days of consultations, recording the lives of patients who didn't end up featuring in the work, I would not have met Johannah Baloyi.

She was a one-woman army, visiting bedridden patients without payment. One of her patients, Martha M, infected with HIV, had begun wasting away. After she began talking with Johannah, she gained five kilos in a week – I saw the proof on a bathroom scale.

Her story was the story of her town. Her husband had vanished, unable to accept the fact that his wife still loved an infected man. Their son and their seven-month old infant were also infected. Johannah brokered the husband's return, a return to love.

This is a portrait of a family with HIV – they are smiling. What you can't tell from the photograph is that husband and wife had spent the day reading to each other at a writing workshop, honest about their betrayals and failings. As I speak, they are moving into their first brick house, built by the government, where Johannah will be a neighbour.

Harvard's Global Equity Centre estimates that Africa needs one million more Johannahs. Without people like her, the ailing rural health system would become terminal.

Johannah became my guide, even after a neighbour accused her of being HIV positive and cut her with his knife. During the five months, she commandeered my vehicle to distribute tens of thousands of condoms. Her sense of humour kept us going through the winter.

Once I woke up in her tin house at 4am, to be in time for an Aids funeral we had to attend, and she cracked that her place was colder than a mortuary fridge. It was. She was the eyes and ears of Dr Cameron, leading him to the houses of patients too weak to get to the clinic. Their relationship became the nub of my story.

One patient that Cameron visits at home is Lydia M. In March, when the nearest district hospital first promised to begin antiretroviral treatment, Lydia had a CD4 count of seven. This measures her

body's ability to fight infection. In South Africa, the cutoff to be eligible for antiretrovirals is a CD4 count of 200. A healthy person usually has a count of 500 to 1 500. By now Lydia is close to zero. This means her immune system welcomes meningitis, pneumonia, tuberculosis, dementia, renal failure, cancers, thrush.

Two weeks ago, she asked Cameron: "Why can't I die?" But her diarrhea cleared up and she is hopeful again. If the clinic had a direct supply of ARVs, Cameron could have begun treatment in 24 hours. His students did a study on the clinic to see if it was ready to handle the drugs. The answer was yes. They also wrote up a database of all HIV patients at the clinic. Half of them needed ARVs immediately.

But the way the health system works is that HIV patients must be referred to the district hospital, Jubilee, 20km away. A few days ago, Jubilee was finally accredited to give out ARVs, probably from September onwards. But it's six months later than promised.

During one week's delay I recorded the deaths of several patients. According to the Health-e news agency, in June, in the most industrialised country on the continent, 42 000 South Africans were on antiretroviral treatment at government sites. (The figure doesn't include non-government programmes.)

In July, Uganda already had 65 000 on treatment. When I was there, in Uganda, I saw one working traffic light in the capital city. One traffic light; 65 000 on treatment. So is the delay here about our capacity or is it political will?

Let's be clear about one thing. This wasn't my agenda. I didn't set out to document the lack of ARVs. My original proposal was to write about their arrival. I kept hoping to interview a patient taking the drugs for the first time but it didn't happen. When Cameron pleaded with the nearest hospital with an antiretroviral programme, in Gauteng, he was told that his clinic is in North-West and besides, they have their own queue.

Rustenburg is in North West, it has ARVs, but it's two hours away. The hospital in Gauteng is half an hour. On maps, the boundary line between the North West Province and Gauteng is literally the fence of Jubilee Hospital. His patients missed treatment by millimeters, the width of the fence. During the five months I spent driving past the fence, it was the boundary between living and dying.

I once met a patient, William M, who had walked to the clinic to prove that he could. It was shortly before the Soweto derby; he wore a Pirates cap and his six-year old son wore a Chiefs jersey. William had recovered from TB, one of Aids' most lethal partners. Cameron had pulled him back from the threshold but only just. He had no laces in his shoes but he was walking again.

I asked him about ARVs. He personified the drugs, like a saviour. "I want him," he said, "But I don't know if I can get him." In Mathibestad, it seemed like we were waiting for Godot, the saviour who never comes.



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Jubilee Hospital has made another promise. I hope it comes true. ARV treatment can buy us more time but it can't be a saviour. The shrapnel beyond the reach of medicine remains.

When I began reporting in Mathibestad, the question I had was simple: When their Aids patients go on dying, how do those in rural health find meaning in what they do? When I met Cameron, a serene doctor, my question became: What is his secret?

But Cameron is frank with the patients and the students who also ask why he carries on: He can't

provide an answer, they need to find their own. "I don't look for meaning," Cameron once told me quietly, after a senseless day of treating Aids without treatment. "I ask myself," he said, "How do I act now?"

And that's the question I want to leave with you: How do we act now? ■

This talk was delivered at the Ruth First Memorial Lecture at Wits on 24 August 2005.