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**Special issue:**

**Reflections on 10 years of  
antiretroviral therapy in South Africa**

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## MESSAGE

# From the Editor

## Looking back while looking forward: A decade of ART in the public sector

In considering the HIV epidemic and its impact, many of our anniversaries are sad ones. Personal anniversaries often mark losses – remembrances of the deaths of family, friends or patients. Clinicians or scientists may mark the anniversary of the first documented AIDS case in a country, or the discovery of the virus itself, but these aren't generally moments for celebration *per se*. So it's not often that we have cause to smile about an anniversary related to the epidemic. However, 1 April 2014 marks one happy anniversary worth remembering – a decade of antiretroviral therapy (ART) in the public sector.

Like many anniversaries, the exact details can depend on where you were, and sometimes dates themselves can be fuzzy. Antiretrovirals were available from the 1990s in the private sector, and a trickle was accessible through trials and small donor-funded initiatives in urban centres from the early 2000s. Some provinces moved more quickly towards making ART available ahead of the National Department of Health, often with the assistance of partners in local and international non-governmental organisations. After the announcement of a national rollout of ART in public sector facilities, some hospitals received supplies of antiretrovirals within weeks. Elsewhere, especially in clinics in rural settings, health services took years to have local providers dispensing ART. Today the number of facilities dispensing ART is expanding still, but most communities across the country have reasonable access, and ART coverage continues to increase. So perhaps this anniversary is not so much a specific date in time, but rather a particular point of inflection in the course of the health service that serves the vast majority of South Africans.

To mark this anniversary, this edition of the Journal is a special issue of sorts. We asked the Society's members, and the public more generally, to submit their thoughts about the ART rollout over the last ten years; and the response was remarkable. We received more submissions than we could publish by far, and thank all those who submitted manuscripts for their time and consideration. And so, rather than our usual peer-reviewed scientific articles, case reports, guidelines and opinion pieces, this issue is comprised entirely of short commentaries by way of reflection, drawn from diverse perspectives from authors working across the country.

In their opening commentary, Gary Maartens and Eric Goemaere<sup>[1]</sup> remind us of the incredible distances traversed during the past decade, and consider what the next ten years may hold. Writing from Bloemfontein, Dirk Hagemester<sup>[2]</sup> asks why the patient-held records, which have become such a routine part of ART and tuberculosis (TB) care for many of our patients, are less than routine for many of our doctors (and readers). In Cape Town, Richard Kaplan and colleagues<sup>[3]</sup> describe how the earliest days of their ART service in Gugulethu consisted of working from a cardboard box in a borrowed office, and evolved

through partnerships with communities, services and academic medicine. Kevin Rebe and James McIntyre<sup>[4]</sup> describe working with the public sector to deliver care to men who have sex with men – a population that remains highly marginalised in many parts of the country and continent.

Many of these contributions are distinctly personal. Caroline Armstrong<sup>[5]</sup> describes working in a Pietermaritzburg hospital before the ART rollout, and how her perspective changed in the early days of providing effective therapy to patients. Joyce Marshall<sup>[6]</sup> discusses how ART began to lift the burden of stigma associated with HIV/AIDS off of her patients, while Michelle Moorhouse<sup>[7]</sup> describes how her general practitioner practice in the Eastern Cape changed when ART became available. Chantél Friend<sup>[8]</sup> uses the AIDS ribbon as a metaphor for the different meanings that HIV has had throughout her career. And writing from the perspective of policy development, Celicia Serenata<sup>[9]</sup> describes her personal travails in contributing to the national strategic plan during 2003.

The challenges of delivering ART in rural communities are reflected from Zithulele in the Eastern Cape Province (Catherine Young and Ben Gaunt<sup>[10]</sup>) as well as Mseleni in northern KwaZulu-Natal (Aurélie Nelson<sup>[11]</sup>). And while ART was a doctor-driven service initially, today nurses initiate and manage the vast majority of South Africans on ART, so it is fitting then that Mzi Tito<sup>[12]</sup> describes the experience of providing ART services in primary care around Port Elizabeth.

One area of dramatic change in the last decade has been in paediatrics, where antiretrovirals have altered the landscape of child health in this country through both prevention and treatment. Here, Ann Moore<sup>[13]</sup> talks about the practical lessons learnt in providing HIV care and treatment to infected children and their families in Cape Town, while Kathryn Stinson and colleagues<sup>[14]</sup> describe the changing paradigms of services for the prevention of mother-to-child transmission (PMTCT) of HIV in Khayelitsha, and the central role that maternal ART plays in preventing paediatric HIV infections. And in the final contribution, Francois Venter<sup>[15]</sup> draws on his experiences of the last ten years to give us lessons for the next decade, with a mix of candour, humour and insight.

Most of the contributions have a tone of celebration (e.g. 'how far we have come!'), and many comment on the revelation that ART represented in the lives of their patients and their own practice of medicine. However, there are also notes of sadness and frustration here – for preventable deaths and ineptitude that characterised much of the response to the HIV epidemic in an earlier period. If we needed a reminder that health and politics are inseparable, we need not look far into the past. And in some places these notes of frustration seem to echo into the present, as ART services become a standard component of primary care in South Africa. With this, the revelations of providing ART for the

first time soon after 2004 appear to be accompanied by the routines of delivering chronic care through the public sector in 2014.

Whatever this anniversary means to you, I hope you find this special issue filled with new perspectives, perhaps a few knowing smiles, and at least one pause for reflection.

Happy reading.

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## MESSAGE

# From the Executive

At the outset, I ask that you forgive my odd poetic licence and mixed metaphors. This describes my journey as an HIV clinician in the decade that has seen us develop the biggest HIV treatment programme in the world.

I clearly remember the first day that our clinic started administering antiretrovirals (ARVs). It was the day that I wrote and passed the exam for the HIV Management Diploma, and I was unable to be at the clinic. It was only on 2 April 2004 that I went to the clinic. I looked in the drug cupboard and realised that we would finally be able to provide South Africans access to life-saving medication. For the next couple of months, as soon as I was finished at the research site where I worked, I went to the clinic at Helen Joseph Hospital to start patients on ARVs. In August of that year we celebrated with cake and tea after we had started our 1 000th patient on treatment.

Then it dawned on me that despite having initiated 1 000 patients in our clinic through all that work, time and effort, on that day the same number of people in South Africa had become infected with the virus. That was when I adopted the so-called 'starfish' approach.

The story goes that a man was walking along a deserted beach at sunset and saw a young boy on the beach, picking something up and throwing it into the water. When asked what he was doing, the boy replied: 'I am throwing these washed up starfish back into the ocean, or else they will die.'

'You can't possibly save them all, there are thousands on this beach, and this must be happening on hundreds of beaches along the coast. You can't possibly make a difference,' said the bystander.

The boy looked down, frowned for a moment; bent down to pick up another starfish, and smiled as he threw it back into the sea. He replied: 'I made a huge difference to that one!'

I loved telling my HIV stories or tales of starfishes: patients arriving looking like skeletons and getting better; my marathon-running HIV-infected patient; and babies so sick they were sent home to die, but having been started on treatment, are now at school. I even coined a term for this in our clinic: 'the Lazarus experience'. And my activist side was fuelled by the ongoing battles with the Mbeki-era denialist and our erstwhile Minister of Health, Manto Tshabalala-Msimang.

However, two things bothered me. The first was that South Africa became the laughing stock at international conferences, despite a growing ARV programme and good research emanating from the country. Quips about beetroot and garlic may have been taken in good humour, but I felt hard done by. We had a good grassroots programme staffed by dedicated healthcare workers who hated to see patients who could have been saved, die. The other was that tossing starfishes back into the sea was no longer enough for me. I wanted a more effective

approach to prevent the starfish from getting stranded on the beach and more effective ways of getting those who were stranded on the beach back into the sea. In retrospect, this was when I changed from being a clinician to more of a public health person.

Fortunately, this also coincided with the end of the 'Manto era', and within a short while, the appointment of Dr Aaron Motaaleli as the National Minister of Health. What the latter has done for the programme is immense. I have highlighted some of the aspects that I have seen in my work as really pushing forward access. Dr Motaaleli decreased the amount of red tape that clinics had to go through to become ARV sites, considerably decentralising the service. We now have over 3 500 clinics in South Africa providing ARVs. His ambitious aim to test 15 million for HIV was achieved. The mean CD4<sup>+</sup> count on presentation is increasing and we are seeing fewer and fewer patients presenting *in extremis*. At the academic ward rounds that I attend every six weeks, we are now seeing older patients presenting with malignancies or long-term complications of antiretroviral therapy (ART). With the review of the guidelines in 2010, stavudine (d4T), a drug we all knew had severe side-effects, was removed from the first line and replaced with the gentler tenofovir (TDF). Finally, the fixed-dose combination means that most patient have to swallow just one pill once a day.

So ten years down the line, what is my role in the ARV programme? As an activist, I am perplexed. The National Department of Health is making all the right noises, but we still need to be vigilant in ensuring that they keep their promises. This includes keeping an eye on stock-outs and making sure that no one is turned away from clinics on the basis of their nationality. I need to keep up with the latest research and do what I can to ensure that when a significant development takes place, it is included in policy. Most of all, I must just do what I can to support the programme with clinical advice, training and advocacy.

While much has been made in the media of getting to zero and the end of AIDS – we are getting closer than ever before – if we let up now, we will see an increase in HIV-

related morbidity and mortality. We need to buckle down and do the work of testing and treating all who come to our doors, and of ensuring that they adhere to lifelong ART.



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## REFLECTIONS

# Building on the first decade of ART

G Maartens, MB ChB, FCP (SA), DTM&H, MMed; E Goemaere, MD, DTM&H, PhD

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There is much to celebrate at the end of the first decade of South Africa's public sector antiretroviral therapy (ART) programme. An estimated 2 million South Africans had started ART by 2012, making ours the largest ART programme globally. ART coverage in adults, according to current guidelines, was estimated at 81% in 2012.<sup>[1]</sup> The prevalence of HIV is increasing, because people receiving ART are living longer.<sup>[2]</sup> In rural KwaZulu-Natal, adult life expectancy increased from 49.2 years in 2003, just before the beginning of the ART programme, to 60.5 years in 2011.<sup>[3]</sup> Tremendous strides have been made in the prevention of mother-to-child transmission (PMTCT) of the virus. Almost 90% of pregnant, HIV-infected women access antiretrovirals (ARVs) either for their own health or for PMTCT, resulting in a 67% decline in new infections in children from 2009 to 2012.<sup>[4]</sup> Further declines in new infections in children should be seen with the new PMTCT guidelines, which include prolonged ARVs for infants during breastfeeding, and combination ART for all mothers irrespective of CD4<sup>+</sup> counts. ART access in eligible children has increased from 17% in 2009 to 67% in 2012.<sup>[4]</sup> We have even started a third-line ART programme.

The birth of our ART programme was difficult, to say the least. We should never forget the tragic loss of hundreds of thousands of South African lives as a result of delays in starting our ART programme. The AIDS-denialist views of former President Mbeki, including the absurd notion that ARVs, not HIV, were the cause of mortality, and the ill-informed promotion of nutrition as treatment for HIV by then health minister, Manto Tshabalala-Msimang, were bitter pills to swallow for people living with HIV, grieving relatives, and healthcare workers. Civil society, notably the Treatment Action Campaign (TAC) and the AIDS Law Project, played a major role in forcing the government to implement ARVs for PMTCT, and later an ART programme. However, once the green light was reluctantly given to scale-up ART, the public sector responded well.

Donors contributed significantly to the setting up and running of our ART programme, but unlike other African countries (except for Botswana), our ART programme is largely funded out of the national budget. The US President's Emergency Plan for AIDS Relief and the Global Fund to Fight AIDS, Tuberculosis and Malaria have played key roles in funding our ART programme and providing technical assistance. Less well acknowledged is the critical role that donor-funded pilot ART projects have played in establishing

the feasibility of public health ART programmes. Particularly noteworthy was the Khayelitsha project, which was jointly funded by Médecins Sans Frontières and the Western Cape government. Three ART clinics were opened in 2000 despite opposition from national government. Generic ARVs were imported from Brazil in 2001, provoking a statement from President Mbeki's spokesman, Smuts Ngonyama, that this was tantamount to biological warfare. The high rates of virological suppression and retention in care of the first two years of the Khayelitsha ART project<sup>[5]</sup> were influential in the initial scale-up of ART nationally and internationally.

**'The AIDS-denialist views of former President Mbeki, including the absurd notion that antiretrovirals, not HIV, were the cause of mortality, and the ill-informed promotion of nutrition as treatment for HIV by then health minister, Manto Tshabalala-Msimang, were bitter pills to swallow ...'**

A reduction in ARV costs has been one of the biggest achievements of the last decade. South Africa is a major global market player given the size of its national ART programme, and the Department of Health has been able to negotiate lower drug prices, to the benefit of other low- and middle-income countries. In 2000, ART cost around US\$10 000 per year, while the currently used fixed-dose combination single tablet for first-line ART costs only US\$129 per year.

South Africa has the world's highest number of people living with HIV, estimated to be 6.1 million in 2012,<sup>[1]</sup> nearly all of whom will require ART in the next decade. The estimated number of new HIV infections in South Africa decreased from 640 000 in 2001 to 370 000 in 2012, which is gratifying, but most people infected in the next decade will also need ART. Major challenges lie ahead to achieve the expansion of the ART programme, particularly if South Africa adopts the new World Health Organization (WHO) ART initiation criterion of a CD4<sup>+</sup> count <500 cells/μl. Task-shifting, such as nurse-initiated management of ART (NIMART), has increased access to ART,

but there is a need to train more nurses. Innovative models of patient care, such as adherence clubs,<sup>6]</sup> should be developed, adapted to local contexts, and rolled out.

**'We know that over 2 million South Africans have started ART, but how many are still in care? ... the massive ART programme expansion needed in the next decade will be accompanied by high attrition rates.'**

The biggest challenge for scaling up ART for the next decade will be retention in care. We know that over 2 million South Africans have started ART, but how many are still in care? Loss to follow-up increased with time and increasing clinic population size in a large South African ART programme,<sup>7]</sup> suggesting that the massive ART programme expansion needed in the next decade will be accompanied by high attrition rates. Measures of retention in care at the facility level need to be collected routinely. Electronic pharmacy refills are increasingly being used and could easily identify people who are defaulting. Retention in care and rates of virological suppression according to years receiving ART should be used to identify poorly functioning clinics and regions.

The initial role for patient activist groups such as the TAC was crucial, given the state opposition to rational treatment for people living with HIV. Some might have thought that the job of activists was done once the national ART programme was launched and the current progressive Minister of Health was appointed. Unfortunately, the general lack of accountability in the public health services, as demonstrated by ongoing

drug stock-outs, demonstrates the need for independent civil society groups to monitor service delivery, and where necessary, exert pressure on the health services to deliver their mandate.

Finally, more resources need to be made available for operational research to support the ART programme. South African HIV researchers have been very productive, but almost all of their major achievements have been completed using resources from international grant agencies. Budgets were made available for research to support the national HIV programmes in the mid-2000s, but this was not sustained. The Medical Research Council has made good progress in leveraging extra funding for clinical research, indicating that political will exists to support more resources for research.

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## REFLECTIONS

# Closer to zero: Reflections on ten years of ART rollout

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To reflect upon ten years of antiretroviral therapy (ART) rollout, one really should set the clock back a little further to see the massive impact of ART on our lives – for clinicians and patients alike. My own journey with HIV began in 1999 when, as a young doctor, I decided to venture into private practice with a local general practitioner (GP) while assessing my career prospects. A week into my new job, the GP went on a trip overseas, leaving me with the following pearls: 'look after the HIV patients and don't let any die before I get back'. I was terrified, as HIV had not formed an extensive part of the medical school curriculum when I trained, and while our exposure to such patients was considerable, we were taught that the only management options were palliative.

So I had a baptism of fire, as the bulk of the practice patient load was HIV, and patients came from many corners of the Eastern Cape to our practice. Many GPs in the region at that time did not have the time or interest to manage these patients and were afraid of attracting stigma to their practices and driving away other patients. Mostly I think that they felt helpless and were not aware of what was happening in HIV medicine outside South Africa. They didn't know that effective treatments were available, and that in the USA and Europe, hospital wards previously dedicated to caring for dying AIDS patients were closing down, because patients were living. HIV was becoming a chronic, manageable disease, and although compared to current treatments, they were more toxic and less tolerable, people were living with HIV. And so, when my partner returned from his trip, all his HIV patients were still alive, and I was filled with passion to learn more about HIV and treatment options. But they were the lucky ones, and not too long after that I lost my first patient to AIDS; unfortunately, the first of many.

Despite the availability of effective treatment, accessibility was still very limited at that time, as was expertise in ART. Antiretrovirals (ARVs) were expensive (triple ART regimens often costing up to several thousands of rands each month). Monitoring tests were expensive. Few medical aids covered HIV treatment, despite the evidence that even with the high cost of ART at the time, treating HIV was more cost-effective than the costs associated with managing opportunistic infections in very sick patients requiring hospital admission. ART was not available in the public sector, so was only an option for those few who could afford to buy medications and pay for the laboratory monitoring tests themselves, or those who had access to clinical trials.

Despite the medications that existed, I still had patients being carried in on mattresses, stretchers, home-made wheelchairs made of garden chairs on tricycle wheels, and I still had to send many patients home with what was palliative care at best. One way of

accessing treatment was through my involvement in clinical trials, to bypass the inadequacies of the prevailing system. I wanted to help as many patients as we could in this way. Consequently, we were seeing two ends of the spectrum: the patients enrolled in clinical trials were flourishing – they were gaining weight, feeling well and returning to work – while others continued to die. This dichotomy was very difficult to reconcile in my mind as a clinician wanting to help all my patients.

More lives were lost due to the pervasiveness of AIDS denialism at that time. The strong stance taken by Thabo Mbeki not only prevented access to treatment, but also resulted in many of those accessing ART through clinical trials or other means stopping their treatment. The Treatment Action Campaign (TAC) was fighting battles on many fronts: demanding access to treatment; campaigning for pharmaceutical companies to make ARVs affordable; and debunking the myths of AIDS denialism – and their fortitude and perseverance prevailed. Finally, in 2004, ART was made available in the public sector.

Fast-forward ten years to 2014. ART is available; treatment guidelines make provision for earlier initiation of treatment; the incidence of HIV is slowly declining; life expectancy has increased; and fewer babies are infected with HIV. South Africa has the biggest ARV programme in the world, with more than 2 million people receiving treatment. Now we have shifted from simply providing some treatment, to providing treatment that is easier to take in terms of toxicity as well as convenience. No longer are we merely trying to save lives – now we aim for quality of life as well as longevity, and our patients are growing old with us. We are watching them start families, and helping them to have children who are free of HIV. Now we are aiming for zero new infections, zero deaths and zero stigma related to HIV. We are making significant strides towards achieving what ten years ago seemed impossible.

Yes we now have some great new drugs, with yet more in the pipeline. And yes, we have managed to build what is, without any doubt, the largest, most successful ARV treatment programme in the world. And yes, we will eventually resolve the logistical issues that result in stock-outs. And yet there are still patients who are presenting just as sick as those I was seeing when I first started treating HIV. They delay testing, or once tested, delay accessing treatment because they fear they will face discrimination and stigma. While we have made such great inroads towards zero new infections and zero deaths, we are not doing as well when it comes to zero stigma. Until we are able to temper and eliminate stigma, zero new infections and zero deaths will remain just beyond our grasp.

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## REFLECTIONS

# Providing HIV care to men who have sex with men in South African state sector clinics

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South Africa's mass rollout of antiretroviral therapy (ART) a decade ago changed the face of the AIDS epidemic in the country. Various populations have, however, not benefited equally.

Treatment programmes have been successful in reaching women, who make up two-thirds of those receiving treatment in state sector clinics, but less so in reaching men.<sup>[1]</sup> This is even more apparent for South African men who have sex with men (MSM), who have historically been ignored for directed service provision, despite being a key population at high risk of HIV acquisition and transmission.

HIV prevalence among local MSM has been estimated at 10 - 43% in various studies.<sup>[2-5]</sup> Until fairly recently, local and regional data were unavailable to inform targeted and appropriate health programming for this population group. South Africa's enabling constitution and government's (SAG's) commitment to providing appropriate care to key populations, including MSM, has provided an opportunity to gather data and develop and implement evidence-based health services.

Anova Health Institute, in partnership with the provincial Departments of Health (DoHs) and with support and funding from the President's Emergency Plan for AIDS Relief (PEPFAR)/ United States Agency for International Development (USAID) launched Health4Men, the first state sector programme aimed at addressing MSM sexual health and wellness.<sup>[6]</sup> The programme includes limited 'centres of excellence' in Cape Town and Johannesburg where large cohorts of MSM can receive direct health services. Data collected from these cohorts are used to develop, test and refine locally responsive and appropriate management guidelines. Operational research is also conducted at these sites, aimed at improving the quality of service and providing the SAG with data to assist in future health planning.

Although important, such centres of excellence are expensive and not scalable. Therefore, the core activity advocated by the Anova model is widespread sensitivity and skills training for healthcare workers already active in state sector HIV, sexually transmitted infection (STI), tuberculosis (TB) and primary health clinics. The aim is to enable them to provide appropriate care for their MSM patients, based on local guidance developed by centres of excellence.<sup>[7]</sup> This competency training has occurred

in four provinces thus far, with plans to roll out nationally in the near future. Currently, six MSM-competent clinics are supported by this project, and many lessons have been learnt from the experience in the field.

Services for MSM can only exist with buy-in from multiple stakeholders. The SAG and provincial DoHs have been responsive to the health needs of MSM at a high level, and have included targeted health services in the country's national and provincial strategic plans. Local HIV, AIDS STI and TB (HAST) managers have mostly been supportive of integrating MSM healthcare skills into their current facilities. Training has been well received by state clinics and MSM training has been approved and integrated into provincial regional training centres. International donors such as PEPFAR/USAID and the Global Fund have developed normative guidance on developing and implementing MSM-targeted services and have been willing to fund such initiatives. Civil society has been able to influence local policy through representation via the lesbian, gay, bisexual, transgender and intersex (LGBTI) sector in the South African National AIDS Council (SANAC). Strong community engagement with groupings of gay/other MSM has created a demand for targeted HIV and sexual health initiatives.

Anova's experience has identified certain factors that facilitate attracting MSM to healthcare services, retaining them for chronic care and reducing HIV and STI transmission risks:

- **HIV services:** Screening for HIV (HIV counselling and testing) should include MSM-sensitive counselling. Counsellors who adopt a judgmental, heteronormative attitude risk alienating clients, thus negating the benefits of counselling. Many counsellors do not ask men if they have same-sex partners and assume only female partners. This results in inappropriate service delivery, resource and time wastage (e.g. no risk reduction occurs if MSM receive counselling on safe penile-vaginal sex but they do not engage in that activity). MSM attending services are particularly concerned about the confidentiality of their information, specifically their sexual orientation and HIV status, and need to be convinced that their private information is adequately protected.
- **HIV treatment services:** MSM should be treated according to the National DoH's ART guidelines, as for any other adult, with a few additional considerations. Due to the efficiency of

HIV transmission during unprotected anal sex (approximately 18 times that of unprotected penile-vaginal sex<sup>[8]</sup>), early treatment should be considered even at high CD4<sup>+</sup> counts to prevent onward transmission of infection, i.e. treatment as prevention. Some subsets of MSM are extremely body-conscious and will not adhere to medications that cause visible side-effects, such as lipodystrophy. One also needs to consider drug interactions with anabolic steroids and other supplements in this body-conscious group. ART agents that cause diarrhoea as a side-effect may cause sexual dysfunction in MSM who engage in receptive anal sex. Adherence support is often complex due to a lack of family support. Substance and alcohol abuse and mental health problems such as anxiety and depression are more prevalent among MSM than heterosexual men. Of importance is that MSM status does not cause mental illness; rather, that depression and anxiety result from the constant stress of being marginalised and stigmatised.<sup>[9]</sup>

- **STIs:** A significant proportion of visits to many MSM clinics are for STIs other than HIV. STI symptoms are a common reason for seeking healthcare in this key population. This should be leveraged in healthcare messaging to attract men into care. Once they attend a clinic, an opportunity for risk-reduction counselling and HIV screening arises. STIs are treated locally according to governmental guidance, which advocates for empirical treatment of various syndromes such as genital discharge or genital ulcer syndromes.<sup>[10]</sup> Attempts to identify the aetiology of the infection and determine antibiotic sensitivity are not advocated. These guidelines are not responsive to the needs of MSM and will likely be ineffective. This is because most cases of gonorrhoea and chlamydia are asymptomatic in MSM and the rate of cephalosporin-resistant gonococcus is higher than in heterosexual men and women.<sup>[11]</sup> The guidelines do not encourage healthcare workers to consider oro-pharyngeal and anal STIs in men.
- **HIV-prevention services:** MSM attending many clinics have reported difficulty in accessing post-exposure prophylaxis (PEP) from mainstream state health services, and many barriers have been identified. These include: most PEP is required after hours when experienced HIV clinics are closed; the need to be screened for HIV (often performed by MSM-insensitive staff who are unable to provide appropriate counselling); and the myth that PEP is only available in state clinics for the prevention of nosocomial HIV or following sexual assault. We firmly advocate for PEP following sexual assault and it is not the onus of a health provider to determine whether or not sexual exposure was consensual.
- **Pre-exposure prophylaxis (PrEP):** PrEP with tenofovir plus emtricitabine is potentially extremely effective at preventing HIV transmission.<sup>[12]</sup> High HIV-risk populations such as MSM, commercial sex workers, drug users and negative partners in discordant relationships should be offered PrEP. PrEP is being offered in the private sector, but no services exist in the state sector; this is an omission that should be addressed.
- **Medical male circumcision (MMC):** This is an effective intervention for preventing HIV in heterosexual men and has been taken to scale by the SAG. Unfortunately, this intervention is less effective in MSM as their main route of HIV infection is receptive anal sex, where circumcision status plays no role. However, there is robust evidence that approximately half of South African MSM also have sex with women and they would derive risk-reduction benefits during such encounters. MMC should therefore be offered to all men, irrespective of sexual orientation, but education and information needs to be nuanced correctly so that men understand the benefits and deficiencies of the procedure.<sup>[13]</sup>

Underlying all of this, community engagement is essential to the success of MSM-targeted health provision. Many local MSM are fearful of health-provider stigma and avoid health services, even if their perception is unfounded. Peer educators and health ambassadors should be deployed to inform MSM of their human and healthcare rights, and to promote access to clinics that have received MSM sensitivity and skills competency training. Community upliftment programmes aimed at raising the social capital of the most marginalised MSM are important.

The Anova Health4men experience has led to the production of a variety of tools that could be adopted by mainstream state sector HIV/ART clinics. These include, among others: appropriately branded condoms and sexual lubricants, information and educational communication materials and instructive manuals for health providers. Anova has made use of a number of technology-lead health initiatives such as its website (<http://www.health4men.co.za>), smartphone site (<http://h4m.mobi>) and a variety of online health and health satisfaction surveys.

We applaud the SAG's current willingness to engage with MSM healthcare and the inclusion of targeted services in our country's health plans. This is especially relevant on the African continent where the attitude of the SAG stands in stark contrast to countries such as Nigeria, Uganda and Zimbabwe, where persecution of gay and other MSM is legally and politically sanctioned and where targeted services providing ART to MSM are almost impossible. We anticipate that the fruitful partnership between the SAG and Anova, as well as other non-governmental organisations active in this field, will continue to allow South Africa to take the lead in providing HIV and ART services to all citizens as a basic human right, in the absence of stigma and judgement.

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## REFLECTIONS

# Within minutes from Mseleni to Cape Town ...

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'It's impossible to roll out antiretrovirals in Africa!' I clearly remember hearing this on a daily basis while studying in Canada 13 years ago. And there were strong points made: too expensive, not enough doctors, risk of resistance, how to monitor patients in resource-limited settings, and so forth. Thankfully, not everyone believed this and we advocated and pressured from all around the world, and the price of antiretroviral therapy (ART) did come down, by more than ten times.

**'... we advocated and pressured from all around the world, and the price of ART did come down, by more than ten times.'**

Ten years later, after studying medicine in the United Kingdom (UK), I moved to Mseleni Hospital in northern KwaZulu-Natal for my 'voluntary community service'. The medical director of the hospital had been there for more than 30 years and started rolling out ART unlawfully before March 2004. He had developed some outreach clinics and managed to have his hospital very well staffed with local and international doctors. With some basic teaching in HIV and tuberculosis (TB), we (the UK doctors) were very soon thrown into the deep end. The first three months of practising were a steep learning curve, particularly in HIV medicine. We were working in the outpatient department where AIDS patients often presented very late, and on the ward where we had very complex co-infected TB/HIV patients with poor referral systems. The mortality due to HIV/TB was often very high. Despite some HIV-positive patients still presenting very late (particularly men), we had good statistics on testing people and good prevention of mother-to-child transmission (PMTCT) coverage.

As part of my duties, I was visiting an outreach clinic weekly called Manaba Clinic. Most of my work there was to initiate patients on ART and to follow up problematic cases. I recall the particular case of a 9-year-old boy who had virological failure on ART, despite adherence reinforcement. After only a few months of working with HIV and ART, and without access to resistance testing, I felt quite out of my depth. Extraordinarily, however, I was able to get advice from an HIV specialist paediatrician in Cape Town within minutes via the national HIV hotline. Following his advice, I started the little boy on lamivudine (3TC) monotherapy as a bridging measure, while waiting for new paediatric formulations to be made available.

A few months later, I saw the same 9-year-old boy and his mother for a follow-up appointment. His viral load was now nearly suppressed and I was going to continue the 3TC monotherapy as per the advice I had received, when mum (via a translator) started objecting. She had always been told that her child must take three antiretrovirals, so why was he taking only one drug? Wasn't there a risk of resistance?

**'She had always been told that her child must take three antiretrovirals, so why was he taking only one drug? Wasn't there a risk of resistance?'**

She made me realise how far we had come in ten years: ART was being rolled out to places hundreds of kilometres from the nearest city; patients with basic education were gaining a good understanding of a complex disease; and expert help from thousands of kilometres away was available within minutes over the phone. Against all odds, what a long way HIV treatment had come!

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## REFLECTIONS

# Ten years of ART in South Africa – how far we have come

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I became involved in the HIV response in 1999, when I joined the HIV, AIDS, STI and TB (HAST) unit within the National Department of Health. Little did I know in 1999 that HIV would become my life. I had already been working in public health since 1993, and had been on the fringes of HIV, through the interdepartmental HIV and AIDS committee. At that point, the focus was on HIV awareness for public sector workers, and success was measured by the availability of condoms.

**‘This was my first exposure to the small world of HIV in South Africa – filled with many interest and stakeholder groups, all with honourable intentions, but not always on the same page.’**

The first task we had after I joined the HAST unit was to participate in the writing of the new national strategic plan (NSP) covering the period 2000 - 2005. This was my first exposure to the small world of HIV in South Africa – filled with many interest and stakeholder groups, all with honourable intentions, but not always on the same page. Fifteen years later, I am happy to say that I think this has definitely changed, for the better.

This is where I was introduced to the process of stakeholder consultation, and through trial and error, we ended up with a document upon which we could all agree. When we wrote that plan, the antenatal seroprevalence rate among pregnant HIV-positive women was 22.4%, with around 4.2 million people living with HIV; and of course, this would climb over the next few years to around 30%, and around 5.6 million people living with HIV. At this point there were no public sector treatment programmes, though there were some patients receiving antiretroviral therapy (ART) in research programmes. However, the NSP 2000 - 2005 put into words the intention to change this, and had as one of its four strategies: ‘Improve the care and treatment of HIV-positive persons and persons living with AIDS to promote a better quality of life and limit the need for hospital care.’

Honestly, we did not really know what this would involve, but the NSP opened the door to allow us to start thinking about it. Unfortunately, it would take another three years for that thinking to be put into action. Following a meeting between then President Thabo Mbeki and former US President Bill Clinton, the then Minister of Health, Manto Tshabalala-Msimang, put together a task team to develop an operational plan for implementing comprehensive care, management and treatment of HIV in the public sector. Bringing together technical expertise from the Clinton Foundation, local clinical practitioners, academics and government officials, we started working for many months to put together what was then a revolutionary plan to introduce ART. I will not dwell on the politics of HIV at the time, but suffice it to say that there were equal amounts of enthusiasm and resistance being experienced at the time of writing the plan.

My life became consumed by writing this plan. The task team pretty much lived out of the sixth floor of a Pretoria hotel. We would work from morning to midnight, catch a few hours of sleep, and then start all over again. Writing, consulting, rewriting, reviewing, submitting for review, incorporating comments, visiting provinces and facilities. And repeat. And repeat. And again.

Draft after draft was critiqued and rejected, but still we kept on going. We did so because we knew that the pay-off was something to which we were all so committed. That period of working with 20 or so hardworking, visionary individuals was the most rewarding professional experience. Ten years after joining the public health sector, I was participating in something that would be revolutionary.

**‘I will not dwell on the politics of HIV at the time, but suffice it to say that there were equal amounts of enthusiasm and resistance ...’**

Through the blood, sweat and tears (it was a 258-page document!), we would come out victorious. On my birthday, 19

November 2003, I received a call from my boss, Dr Nono Simelela, with the best five words I could have wished for: 'Cabinet just approved the plan!' This was before 10 am in the morning. I went to the nearest bar, and had a large cocktail to celebrate.

**' ... with vision, collective response and commitment, we can overcome obstacles for the improvement of the health of all who live within the borders of South Africa ... '**

Once the plan was approved, we seemed to move at warp speed. Putting in place the budget, people and systems to introduce ART in the public sector required a monumental effort from government, clinicians, advocacy groups and civil society in general. Participating in facility visits to ensure that everything was in place to initiate patients, the massive training effort that had to be rolled out, job aides, guidelines – it was intoxicating. When Thursday 1 April 2004 rolled around, it felt like the culmination of something that started in mid-1999 when we started working on the NSP.

I was also there when another Minister of Health, Aaron Motsoaledi, inspired us to think bigger, collectively, by pushing for the decentralisation of treatment from mainly hospitals to primary healthcare services. By April 2010, treatment was offered in fewer than 500 facilities – by the end of 2013 that number had risen to over 3 500, and the number of people receiving ART, from under 1 million to over 2 million.

I look forward to the next challenge – with more than 5.6 million people living with HIV, there are many more millions that need to be initiated on ART in the next decade – and this within the existing public sector constraints. However, knowing where we were ten years ago, I have faith in our ability, collectively, to make this happen successfully. As a society we have shown that with vision, collective response and commitment, we can overcome obstacles for the improvement of the health of all who live within the borders of South Africa, and I hope to be a part of this for the next decade, and beyond.

**Conflict of interest.** This work is written in Ms Serenata's personal capacity and does not necessarily represent the views of the Clinton Health Access Initiative.

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## REFLECTIONS

# Reflections on HIV care and ART – a view from Pietermaritzburg

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I held her hand; her wasted arm revealing the anatomy of every bone and muscle. Her eyes were closed, weighed down by the burden of disease. She lay upon the bed in my consulting room and there, with no fanfare, she breathed her last breath, passing effortlessly from life into death. Ironically, it was 1 December 2000, World AIDS Day. The patient was a nursing sister and her decline in the face of no antiretroviral therapy (ART) had been harrowing. At times like these, the futility of working in an HIV clinic was overwhelming, and I fought tears as I turned with a heavy heart to deal with the devastated family as best I could.

I had arrived in KwaZulu-Natal from my native Britain in 1997 to work for two years. I soon realised that the numbers of HIV-infected people were growing inexorably, but that no-one really knew what to do with those individuals who had summoned the courage to take an HIV test and had a positive result. Triple-drug ART was new, even in Europe, and virtually unheard of in the hospitals in which I was working. Knowledge about the natural course and management of HIV was limited, even among healthcare professionals.

On the wards if a patient had 'the label' (coded in various subtle ways in the doctors' notes), then doctors and nurses would often not fully address whatever the presenting problem was – even if it was unrelated to HIV. There would be hushed tones on the ward round, a shrugging of shoulders and a general feeling that there was nothing much more that could be done. Little wonder that time and again patients would refuse to be tested, even in the face of all the stigmata of advanced HIV infection. Because, at that time, to test positive meant that your medical team might have looked no further for what was actually wrong with you. In effect, you would have been sent home to die.

It seemed that we doctors hated the diagnosis almost as much as the patients did. It called us failures; it labelled us as incompetent, inept, ineffectual; it mocked our training and humbled us as we fought to cope with the burgeoning numbers inundating our services. We had no oral antifungal agents – just gentian violet. Amphotericin B was extremely difficult to obtain and cryptococcal meningitis, when the diagnosis was actually made, was almost universally fatal. There were virtually no HIV services, and patients were often literally neglected as they trod the terrifying path of opportunistic infections to their death.

In 1999, I started working at a government hospital in Pietermaritzburg. There, an insightful and committed physician had started an HIV clinic (one of the first in KwaZulu-Natal) and I remember clearly how incredulous and excited I was about this! Someone was willing to see these patients; someone actually *wanted* to see these patients! Someone felt they had something to offer in the face of the HIV monster which had thus far defeated all the doctors I knew! I was captivated by the thought and it was not long before I joined the clinic. Although we had no antiretrovirals (ARVs), we provided something that these patients hadn't hitherto experienced: a place where they were welcomed *because* of their HIV status.

**'It seemed that we doctors hated the diagnosis almost as much as the patients did. It called us failures; it labelled us as incompetent, inept, ineffectual; it mocked our training and humbled us as we fought to cope with the burgeoning numbers inundating our services.'**

Elsewhere in society and in the healthcare system at that time, people living with HIV were rejected and ostracised. But in an HIV clinic, they were embraced. We got to know and care about our patients; we treated their opportunistic infections; we obtained disability grants for them; and we spent many hours counselling about death and dying, allowing people to explore and verbalise their fears. We encouraged mothers to make memory boxes for their children and we galvanised patients to put their affairs in order before they died.

We tried to read as much as we could about HIV management; we gave isoniazid and cotrimoxazole prophylaxis and we obtained a supply of ketoconazole for oesophageal candidiasis. There were so many things we didn't know. The internet was limited and we relied heavily on our manuals to teach ourselves HIV medicine. It became increasingly obvious that ARVs were going to be the only solution for our burdened country. How many heated discussions were had around this topic! Many people felt that such an expense could never be borne by a middle-income country with such a vast HIV epidemic.

**'Although we had no antiretrovirals, we provided something that these patients hadn't hitherto experienced: a place where they were welcomed because of their HIV status.'**

In 2000, we started prescribing the cheapest ARV drugs in a desperate attempt to do something that could slow down the disease progression. And so Bongani, weak and wasted, with histoplasmosis of the palate, was our first patient to receive didanosine (which he paid for) and hydroxyurea (which we supplied). Amazingly, he blossomed on what is now considered substandard, toxic dual therapy, and we marvelled in wonder at his improved health! This was the first time we had ever seen the disease checked and reversed.

Next, didanosine and stavudine became available for US\$1 per day. This was affordable to a number of patients and it worked! It was relatively durable and we saw people rally. Very few people in South Africa at this time knew much about HIV treatment. We constantly felt like isolated and lonely pioneers, chasing the pipedream of triple therapy. Those were the days when the government dragged its collective feet in almost everything concerning the treatment of HIV and the Treatment Action Campaign had to force them into the courts.

Later, the advent of relatively cheap efavirenz meant that at last we could initiate patients on really effective ART. The caveat of course was that they had to pay R700 for one month's supply. Those who could afford it sat side by side with those who couldn't, which was a huge

source of frustration for all of us. We continued to be astounded by the effect that these drugs had on our patients. After so many years of losing countless lives, at last we had a weapon with which to fight back, and it was a glorious feeling. We still lacked adequate monitoring (it was difficult to convince people to spend R750 testing their viral load privately) and we learnt hard lessons as we saw peripheral neuropathy, lactic acidosis and drug-related deaths.

Early in 2003 the air was thick with rumours that soon the government would introduce a national ART programme. When the moment actually arrived, it was a cause of great celebration. The package was comprehensive and at last we could monitor patients' responses to therapy. Our KwaZulu-Natal Department of Health seemed really committed, with our Minister of Health, Dr Zweli Mkhize, even coming to work at the clinic on Monday mornings!

**'After so many years of losing countless lives, at last we had a weapon with which to fight back ...'**

I still work with HIV – having been privileged to have witnessed the enormous mobilisation of resources and commitment that has brought us to where we stand today as a country. The HIV story of South Africa continues to evolve, but for me, the battle will never be as fierce again.

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## REFLECTIONS

# A nurse's perspective on the ART rollout

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The introduction of antiretroviral therapy (ART) brought about an exciting, yet somewhat scary period in terms of treatment and care in our health facilities. In 2004, when the rollout of ART started, I was fortunate to have been working in one of the first facilities to be accredited as an ART site in the Nelson Mandela Bay Metropolitan district. Only one registered nurse was trained in the ART programme; she became the 'queen' of the programme and the envy of the rest of the colleagues, as suddenly she was elevated to a specialised position. There was new terminology that we had to get used to, and the names of the new drugs were so many and complex that I thought I would never be able to pronounce them, let alone remember them. Drug names like 'stavudine' and 'lamivudine' sounded like some eastern European names!

**'... the names of the new drugs were so many and complex that I thought I would never be able to pronounce them, let alone remember them.'**

Early on, there were rumours making the rounds from some media and within communities that these drugs were actually very potent, toxic and dangerous to the patients – and this did little to attract some nurses to the ART programme. In fact the envy towards our trained colleagues turned to pity, because in our view, they were treading on dangerous ground (sometimes nurses can be reluctant to take professional risks for fear of medico-legal implications). Coupled with our lack of training in those early days, this ignorance instilled fear and doubt in many of us.

Yet throughout this, the number of clients receiving ART began to grow significantly. This impacted on space, as waiting areas were overflowing with ART patients. Facility managers faced several health systems challenges that had not been faced before, and planning for facilities became more difficult. This also posed a serious challenge to the facilities as nurses saw the increased patient health needs as an added burden and workload on the already overburdened staff; and this was

compounded by a gross shortage of staff in general. In facilities where there was only a single nurse trained in initiation and management of ART, that person would burn out sooner or later due to increased workload. And when a lone nurse trained in nurse-initiated management of ART (NIMART) was off sick or on leave, there was often no one trained to take over from her.

**'... there were rumours ... that these drugs were actually very potent, toxic and dangerous to the patients – and this did little to attract some nurses to the ART programme.'**

In this context, I volunteered to become part of the ART programme. For me it was a great opportunity to become involved and I was mentored by a trained NIMART nurse while working alongside her. Working with patients receiving ART became a rewarding and fulfilling experience in my professional life. Soon I was able to breeze through the names of the drugs like an old expert! It was rewarding to see clients who were brought to the clinic unable to walk, some even in wheelbarrows, starting ART, and a few weeks later walking into the clinic unassisted and smiling. I was fortunate to work alongside a team of very capable and intelligent community health workers who had been trained in various aspects of the programme, and of course, fellow NIMART nurses who were pioneers in the programme.

Today a large number of people living with HIV are receiving ART and the number is growing each day. It has been incredible to witness the process unfolding right in front of my eyes, with all the excitement of seeing people's lives transformed in front of you: patients who would have died, coming back after receiving ART to live normal and healthy lives.

Ten years of ART has changed a lot of lives for the better and has impacted positively on many communities.

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## REFLECTIONS

# Reflections on six years in paediatric ART

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As part of my work at a primary care clinic in Khayelitsha, I started the paediatric arm of the antiretroviral therapy (ART) service in our clinic six years ago. When I first started, many children were being cared for by family members or foster carers because their mothers had died. This is now the exception, as most mothers receiving ART survive. Today, the numbers of patients are still relatively small compared with those in many other programmes, although there are now over 210 children, with a further 10 - 15 adolescents having graduated to the adult ART section. Over time, this had the advantage of allowing me to get to know the families and essentially to function as their general practitioner. In terms of the model of care, a doctor (myself) starts all the small children on ART and then passes their care on to the nursing sisters when they are stable and about 3 years of age; I continue to see the children with clinical problems until they are stabilised. This approach is obviously not possible in many parts of our country, but has had many advantages.

Some of my reflections on spending time in primary care services for paediatric HIV include:

### Adherence and support

I have cared for a lot of children from a local children's home who have made a brilliant control group, as they are all suppressed as a result of getting their medication on time every day. This demonstrates the importance of adherence to treatment regimens. I have even used the home temporarily for children who were failing their regimens – once suppressed, they were returned to their families, who had in the meanwhile been educated to ensure better adherence. One child, placed there voluntarily by her mother because of concerns about carer adherence, continued to show a detectable viral load. Having proven that it was not due to a lack of adherence, we could confidently place her on treatment with second-line drugs; she subsequently suppressed, indicating that she had developed resistance.

### Disclosure

Disclosure is often a problem, by the mother to her family as well as disclosure to the child. I believe that we need age-appropriate support groups to assist in this. Small children grow up into big children and adolescents, and they need progressive disclosure so that they are fully informed about their status well before puberty. Disclosure is often a particular

problem with the very young mother (who may be scared to tell her own mother her status), or the working mother (who may not want her employer to know and does not want to take time off work to come to the clinic; the family may be dependent on her work income and so she does not want them to worry about her health status).

### PMTCT

In contrast to previous years, the prevention of mother-to-child transmission (PMTCT) of HIV programme is now so effective that few babies become HIV-positive; but those who do frequently pose real problems. They are often born to young mothers who have not disclosed their status and/or have poor home circumstances. These mothers need intense counselling and support, especially for the first few months, as there is a high drop-out rate, especially if they have not yet disclosed their status to their family. Mothers often have difficulty accepting the positive status of their child, as they no longer expect it.

### Mobile populations

We serve a very mobile population who constantly transfer in and out of the clinic, with or without informing the clinic. Often clients are called away unexpectedly (e.g. to a funeral in another province) and they do not think about, or do not have time to come to the clinic for medication before departure. The National Health Laboratory Service (NHLS) is sometimes a good resource when trying to ascertain a client's previous history, as we can track where blood samples have been taken! I have found this helpful when trying to find out more about an abandoned child. This, however, illustrates the need for a national database or a Medicalert-type card where clients could voluntarily access their medication anywhere. They would also then be recorded as compliant by collecting their medication.

### Defaulters

The computer programme that we utilise (TIER.net) has a system for following up defaulters, but in practice this is not well implemented for various reasons. One reason is the delay in data capturing. It would be helpful if each clinician had a desktop computer, to allow data to be updated during the consultation. I have kept my own computer records on my laptop, as well as an appointment book for consultations, which has helped me to keep track of my patients. I have found that I received a good response from those mothers/carers whom I texted personally quite soon after they defaulted (one week

later) and I think this was partly because they felt a sense of personal interest from 'their doctor'. Once they have defaulted for a long time, they are often too embarrassed to return, but a text message, even at this late stage, may give them a reason to return to the clinic without losing face. It certainly does not help to get angry with defaulters as there is usually a very valid reason for defaulting, such as problems in the family, and these need to be dealt with as part of the greater model of care.

### Seeing the same clinician

Seeing the same clinician at each visit has many advantages. If possible, this is a much better system as it leads to good clinician/patient/family interaction and usually results in better adherence. It can be organised to an extent by making appointments on certain days for specific clinicians.

### Neurological side-effects

The neurological side-effects of HIV are considerable. Children with major impairment are appropriately referred to special schools, but those with minor impairment (and this is a large proportion of children receiving ART) remain in mainstream education with little, if any, assistance. There seems to be very little in place to help the children with minor impairment and this will need to be addressed urgently by educational authorities.

### Clubs for children receiving ART

This would be of considerable value for stable children. Maybe, one for pre-schoolers, one for primary school and one for high school/

teenagers. Occasionally, it would be helpful to have carers and children together, and sometimes to have them separate. In this way, issues such as progressive disclosure could be dealt with in an age-appropriate manner, together with other issues that affect the specific age groups. Teenagers are a particular challenge. They need lots of support and interaction to prevent them from defaulting, as well as lots of input about sexuality and their responsibilities in this regard. Teens at school find it difficult to miss school to come to the clinic. A possible solution would be to evaluate the stable ones clinically only four times a year (in the school holidays) with their carer collecting their medication in between.

### Treating the entire family

I have found it very helpful to treat both mother and child in the same consultation, essentially offering a one-stop-shop. This way, the mother's time in the clinic is minimised and the clinician gets to know the family circumstances. This is an essential part of treating patients as their social circumstances have a considerable impact on how they perform on treatment. In one particular case, I treat both parents and their child.

It has been interesting and stimulating to be in the field of HIV medication, particularly with regard to treatment in children. The management has come a long way, but it is an evolving field and there is a long way to go yet.

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## REFLECTIONS

# 'They dropped the blanket of their fear': Reflections on HIV medicine in South Africa, 2014

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Coming from a community health background in KwaZulu-Natal and the informal settlements around the Grasmere toll plaza, I was working in occupational health in the late 1990s and seeing a number of truck drivers with all the clinical features of HIV/AIDS, and feeling frustrated at how little we could do for these patients. Then I sustained a needle-stick injury with HIV-positive blood in 1997. Spending a nauseous month on Combivir, I became aware that HIV had come to visit me and my family. What was this experience saying to me? It was calling me to engage.

As I reflect on the past two decades, we have lived through seismic shifts in our medical understanding and management of the infection. I recall watching a polymerase chain reaction viral load being reduced to nearly undetectable levels in eight days in one clinical trial that required weekly testing in the first six weeks. From an inevitable death sentence, we have moved to being able to offer our patients chronic disease management and wellness. The costs of antiretrovirals and monitoring have dropped significantly.

In the occupational health world, we have integrated HIV testing into our periodic medicals along with blood pressure and fasting glucose. Each company with whom we work, has

a policy on HIV/AIDS – including non-discrimination. There are peer educators and ongoing education on the factory floors.

**'Then I sustained a needle-stick injury ... Spending a nauseous month on Combivir, I became aware that HIV had come to visit me and my family ... It was calling me to engage.'**

But perhaps the most profound observation has been to watch people 'drop the blanket of their fear'. This happened slowly in support groups and with one-on-one encounters with patients in the early part of the millennium. But the rate of change has accelerated. Recently, for World AIDS Day, I spoke at a company with one of my patients who shared her 'Lazarus' story. Three people came up to her and disclosed their status and requested to join the support group.

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## REFLECTIONS

## Reflections on a decade of HIV in my life

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The red HIV ribbon is an almost universal icon for the HIV/AIDS cause. I see the HIV ribbon in four different ways as I reflect on the different periods of work in my medical career thus far.

Firstly, I see the red ribbon upside down, just like my head was firmly ostriched in the ground soon after qualifying in the Western Cape. There was one ward right at the top, out of the way of a medical intern's rounds, where all *those* patients went to die and at least I didn't need to worry about a 'resus' in *that* ward. But, towards the end of 2003, my interest was piqued when a few of the respected medical officers were heading towards HIV care. That was forgotten though when I started private general practitioner work with not a single HIV-positive patient, until one routine insurance test came back positive – one devastated patient!

But then the ribbon turned on its side as I moved to the Eastern Cape and worked for a non-governmental organisation. The number of devastated patients there could not be counted. I quickly had to learn to swim in the deep sea of HIV treatment. There were days when I almost drowned, like the day I was summoned into a small room full of people and was called a racist for limiting (extraordinarily long) tea times in order to get through the patients first. As a team we thrashed it out in that dark room, and going forward we became a centre of excellence in our area, not only for our work, but also for our love for each other. We saw an entire town rally around us by providing soup, toys for the children, beautiful paintings and more. But most importantly, I saw life after HIV: a man on death's door walking back to work in a few months; a skeleton of a child smiling with her new toy after a few weeks of antiretrovirals; and Venus, who encouraged me at every consultation, despite being left blind and in a wheelchair after cryptococcal meningitis, and deserted by her family, but just managing to force the words out of her facial-palsied mouth, 'thank you'.

Thirdly, on moving to KwaZulu-Natal and working for the Department of Health, I turned the ribbon upright. A handful of doctors slaving away at the heart of the epidemic, seeing upwards of 80 patients a day. Clearly this was not sustainable, so we embraced nurse-initiated management of ART (NIMART). We worked within our crippled system, taking the literal '*iskoro skoro*' (old broken car) on the road to the rural areas in our

district to present our hopeful plan to all the clinics. And, lo and behold, it worked! This gave us the opportunity to look into quality: checking viral load trends intensively, training nurses, evaluating resistance patterns and fighting with (but more accurately for) non-adherent patients. And then all too soon I left behind the teenager who kept me busy on Mxit but lied to my face about adherence, and the many others who influenced my thoughts on HIV in one way or another. Unfortunately, I still bump into them every now and then in Pick 'n Pay or at the local nursery, where I get an update on CD4<sup>+</sup> counts from mom and the grades of her healthy little boy.

**'But most importantly, I saw life after HIV: a man on death's door walking back to work in a few months; a skeleton of a child smiling with her new toy after a few weeks of antiretrovirals; and Venus, who encouraged me at every consultation, despite being left blind and in a wheelchair ...'**

And lastly, after seeing one too many a sick child not cared for by mom, another unplanned pregnancy, the dreaded positive polymerase chain reaction test in a 6-week-old baby, there came a point when I started asking, 'What now?', 'Where to from here?', 'How do we stop this?' And that is when the red ribbon started to look more like an arrow pointing firmly towards HIV-prevention research. I am now privileged to be involved in two promising phase-three trials looking at conquering the transmission of HIV in females. There are, however, days when I feel like pointing the red-tipped arrow firmly at the participants (figuratively speaking, of course) who indulge in risky behaviour after the team's best counselling efforts. Fortunately though, I mostly see the big picture of South Africa leading the world into 'Getting to Zero', with the red arrow firmly pointed towards the '*icilwane*' ('gogga', virus).

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## REFLECTIONS

# Providing high-quality HIV care in a deeply rural setting – the Zithulele experience

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In the deeply rural Zithulele community, based in one of the poorest districts in South Africa, the clinical and HIV programme staff believe that despite our resource-poor, rural setting, our patients deserve the same quality of medical care as their compatriots elsewhere. As a result, the HIV service that we have developed over the past seven years has had a strategic emphasis on providing accessible, quality care delivered in an innovative way that addresses local challenges and builds a robust foundation for future growth and sustainability. While our challenges are not unique, rural health facilities are often fragile entities. They have low staff numbers, yet carry a relatively heavy responsibility. In these parts, there is no plan B unless you devise it yourself!

Various aspects of the programme have evolved over time and have been modified, as we have learnt from our experiences, as the programme has expanded, and as the HIV climate has changed over the eight years since we started our first patient on highly active antiretroviral therapy (HAART) with the assistance of our neighbouring hospital. Specific aspects of our rural reality that have informed the innovations we have brought to the model of care include:

- **Fragile clinics:** There is high staff turnover, significant problems with procurement, an isolated work environment and lack of on-site clinical and systematic support. While staff receive training in clinical and policy implementation, this is often rote learning and ongoing mentorship is essential to bring depth of understanding. Zithulele staff provide strong links between the clinics and hospital, improving access to expertise and morale among clinic nurses.
- **Mobile patients:** Our large, still-growing number of patients are extremely mobile, with a lot of patient movement both between facilities within the programme borders, but also in and out of the geographical area due to migrant labour. A uniform system that works effectively across all sites and that is easy for patients to access from any programme facility has been critical to avoid confusion and to ensure continuity of care.
- **Drug supply:** In common with many other areas, our primary healthcare facilities have struggled to maintain continuous access to medication and other stock items. (Everything

from paracetamol to antibiotics to ART for the prevention of mother-to-child transmission (PMTCT), as well as needles, HIV test kits and more, has been out of stock at some point over the years.) Not only is our district hospital committed to supporting primary healthcare, it is a resource-efficient and economically viable approach to link hospital and clinic care in order to prevent more complicated, expensive care at hospital level due to stock-outs at clinic level.

Preventing resistance in a context where drug regimens are limited and advanced treatment regimens may be difficult or impossible to access is critically important, both from a programmatic and individual patient perspective. More information on how we do this is included in the model presented below.

In light of these issues, we realised early on that while our programme requires an element of flexibility to meet the needs of a rural community, it also needs: to ensure that high quality, comprehensive care is accessible to all; to be stringent enough to promote adherence to lifelong treatment; and to provide an effective method of monitoring patients. We are privileged to have had access to resources that made it possible to avoid compromise on any of these aspects. Operating within a public sector context has also meant that any model that we implemented needed to meet national priorities and be flexible enough to adapt as these priorities change over time.

The HIV care model implemented across the Zithulele catchment area is outlined in Fig. 1. Programmes are always about more than just the numbers, but these indicators demonstrate how the model illustrated successfully provides high quality, accessible care:

- Large number of patients receiving treatment: as of end October 2013, 3 785 patients were receiving treatment, including 269 children; and over 5 000 patients have been initiated on antiretrovirals (ARVs) since 2005 (large numbers transfer out, often back to the mines)
- Ninety-one per cent of patients in the programme collect from their facility of choice: those patients who remain receiving care at the hospital are either those who require hospital-level intervention or those who choose, for reasons of their own, not to receive treatment at a clinic

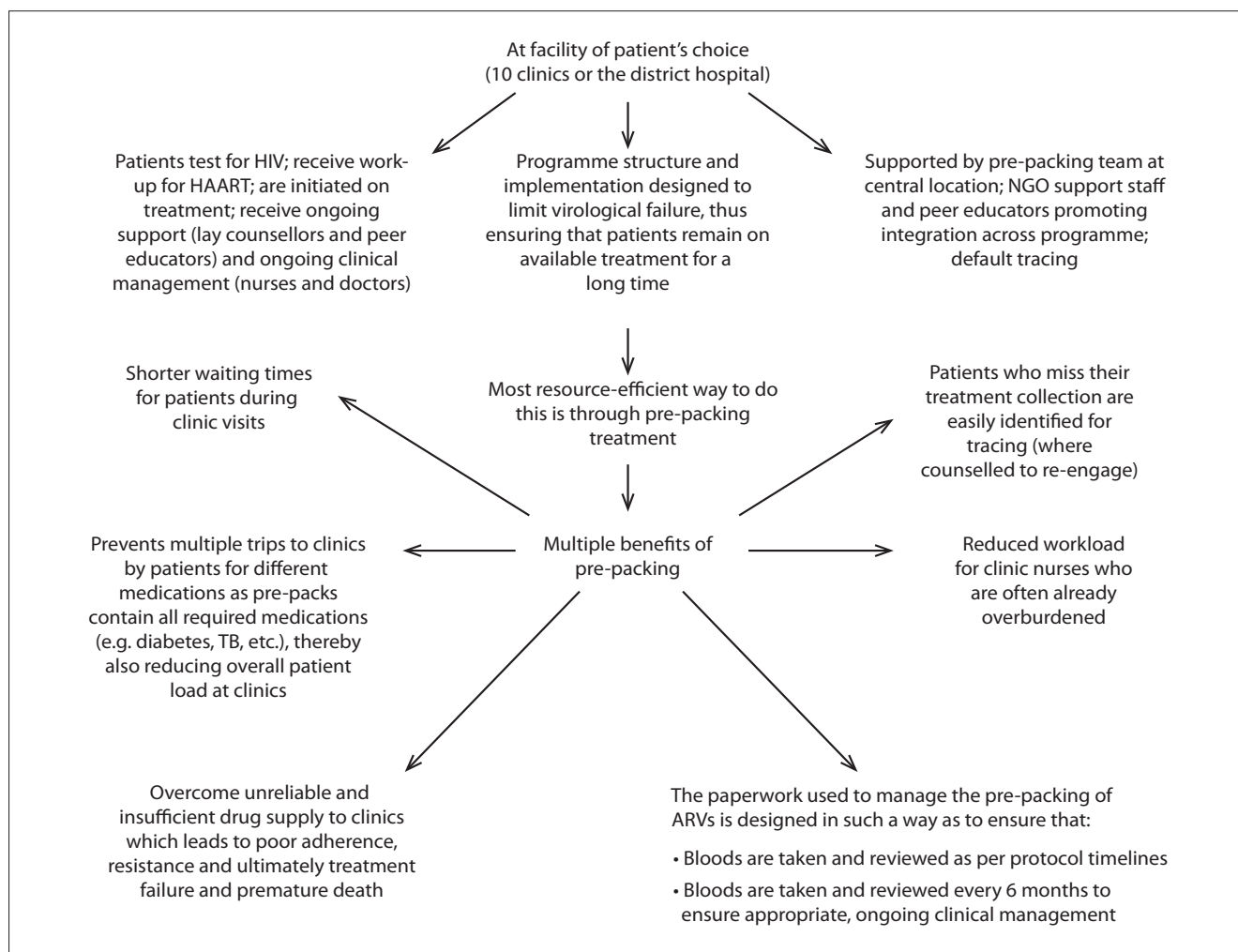


Fig. 1. Service delivery model of HIV care at Zithulele Hospital. (HAART = highly active antiretroviral therapy; NGO = non-governmental organisation; TB = tuberculosis.)

- There is no waiting list to start ARVs at any facility, whether hospital or clinic, and patients can be initiated on treatment by doctors or nurses on any day of the week
- Excellent viral load (VL) protocol compliance: the results of a recent VL audit (a randomised review of half of the programme facilities) showed that in the past year, 92% of patients had a VL measurement performed on time – this is a significant achievement, especially considering the recently introduced changes in protocol
- A recent audit showed that 91% of our adult patients are still receiving first-line treatment and 94.5% of these have a suppressed VL (and 91% of all our active adult patients currently have a suppressed VL)
- No patient in the programme has ever been turned away without their full regimen of treatment – a momentous achievement in a district and province where ARV stock-outs have made regular headline news.

The government has focused on expanding programmes across the country, with energy and resources being directed towards ensuring access for all who need treatment. However, given the challenges outlined above and in line with our philosophy that rural care should not be second rate, we have emphasised the need for *accessibility to quality care*. The way we have designed and structured our programme, particularly our adoption of pre-packing medication from as soon as we started to provide decentralised, clinic-based care, has not always

been well understood or received by middle managers who occasionally misinterpreted national policy as a one-size-fits-all directive. Nevertheless, the outcomes that have been achieved demonstrate that the long hours spent negotiating have been worthwhile.

As far as possible, we work within the existing structure and resources of the Eastern Cape Department of Health (ECDoH), but implementing the above programme does require some additional funding. Non-governmental organisation (NGO) support has made this possible, and in the current budgetary climate, continued NGO support remains essential to maintain this model. However, with the attention we are giving to strengthening and supporting the ECDoH systems and structures, and with an imminent expansion of government-funded prepacking, it is hoped that over time we will be able to maintain this standard of care without outside support.

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## REFLECTIONS

# Reflections on a decade of delivering PMTCT in Khayelitsha, South Africa

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## Implementation of a flagship PMTCT programme in Khayelitsha

Great progress has been made in the prevention of mother-to-child transmission (PMTCT) of HIV in the past ten years in South Africa, and this is reflected in the achievements of the health services in Khayelitsha. Located 56 km from the centre of Cape Town, Khayelitsha has an estimated population of 500 000, with a 38% unemployment rate. Forty-five per cent of the population live in formal housing. Antenatal (ANC) HIV seroprevalence increased from 19.3% in 2000 to 37% in 2011 and is the highest in the Western Cape.<sup>[1]</sup>

The Provincial Government of the Western Cape (PGWC) started the first PMTCT programme in South Africa in Khayelitsha as a primary-healthcare-level demonstration project on 4 January 1999, despite opposition by the National Ministry of Health. The School of Public Health and Family Medicine at the University of Cape Town was tasked with the monitoring of this pilot, and in September 1999, Médecins Sans Frontières (MSF) added technical support. Voluntary counselling and testing (VCT) was provided at one midwife obstetric unit (MOU) and short-course zidovudine (AZT) was dispensed by midwives from 36 weeks of gestation and during labour. Later the pilot was extended to a second MOU, and in 1999, 74% of pregnant women agreed to testing and 16% were found to be HIV-infected.<sup>[2]</sup>

Initially, antiretrovirals were provided only to prevent transmission to the child. Maternal AZT was stopped after delivery and no further HIV services were available for treating the mother. Continuity of care was poor as ANC and postnatal child health services were fragmented and provided by different health authorities. A clinician at the time recalled, 'On learning they were HIV-positive, women would commonly ask, "When am I going to die?" All we had to offer was treatment to reduce the risk of the baby being infected, but no treatment to keep the mother alive, to see her child grow up.'

After complex negotiations in February 2000, MSF opened the first service for pregnant, HIV-infected women requiring antiretroviral therapy (ART) in Site B. MSF extended the HIV

services and ART to everyone who was eligible, according to World Health Organization (WHO) guidelines, and to two further sites in Khayelitsha. However, legal and regulatory barriers to generic antiretroviral imports delayed service implementation and drug supplies until 2001. Postnatal women from the PMTCT programme initially constituted the majority of ART referrals.<sup>[3]</sup> Nine postnatal clinics provided free formula milk for those who elected to perform replacement feeding.<sup>[2,4]</sup>

**'... women would commonly ask "When am i going to die?" All we had to offer was treatment to reduce the risk of the baby being infected, but no treatment to keep the mother alive, to see her child grow up.'**

Despite scientific evidence on the effectiveness of PMTCT, the AIDS-denialist views of President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang led to a significant delay in the development of the national PMTCT programme, resulting in thousands of infant infections and subsequent deaths. In a landmark court case brought against the government by the Treatment Action Campaign (TAC), nevirapine (NVP) was made available nationally by order of the Constitutional Court in 2002 and a national PMTCT programme was implemented. NVP was the regimen established in two 'pilot sites' per province. The implementation of the national programme was slow, with wide geographical variation. By this time, the Khayelitsha PMTCT sites were well established, and VCT coverage was over 95%.<sup>[3]</sup>

## Implementation of more efficacious PMTCT regimens

The Western Cape was also the first to launch a province-wide PMTCT programme by 2002/2003. Faced with a difficult choice

between national policy at that time (single-dose NVP) and the more complex regimens, such as AZT from 28 weeks of gestation with the addition of single-dose NVP, a technical meeting was held with policy makers, researchers and clinicians, including representation from the Perinatal HIV Research Unit (PHRU) and the French National Agency for AIDS Research (ANRS). It was decided that both interventions were equally effective. The MSF-supported Khayelitsha sites moved to the more complex regimen in 2003, consisting of AZT from 28 weeks of gestation and single-dose NVP given to all HIV-positive mothers in labour and to infants post delivery. The effectiveness of this programme at a primary care level was demonstrated in Khayelitsha in 2004, when PMTCT coverage was reported to be 77% and mother-to-child transmission 8.8%.<sup>[5]</sup>

While the national PMTCT programme continued to supply single-dose NVP for pregnant women, the Western Cape provided both AZT and NVP in 2004 and enhanced the PMTCT programme by expanding it throughout the province as a nurse-driven service within ANC services and the MOUs. Lessons learnt from programme implementation assisted the early development of ART services for adults and children in the province.<sup>[6]</sup> Following delivery, women were referred to the three MSF-supported ART sites in Khayelitsha, and new sites were established in 2003 in Khayelitsha, Langa and Gugulethu, in addition to secondary and tertiary facilities. When the national provision of ART was announced in 2004, organisations within the Western Cape had already changed priorities from demonstrating feasibility to targeting scale up and service integration.

### Towards an integrated model of care for pregnant women requiring ART

In 2004, the Western Cape PMTCT protocols were changed to include CD4<sup>+</sup> count testing and referral of pregnant women with a CD4<sup>+</sup> count  $\leq 200$  cells/ $\mu$ l, or WHO stage 4, defining conditions for ART initiation. The treatment and care of pregnant women with advanced disease had been a part of global PMTCT strategy since 2002, yet there was little evidence on the best approach for implementing ART for pregnant women within vertical ANC services in resource-poor settings. Integrating the initiation of life-long ART in pregnant women into ANC services at a primary care level posed several challenges, including laboratory monitoring requirements, multiple ANC visits, linkage to postpartum ART, and clinical skills to manage both pregnancy and HIV.

Initially, pregnant women were referred to an existing ART clinic before delivery. However, many women failed to link to care or did not receive ART timeously. Patients also complained of the burden of additional visits to fetch their treatment, as well as of transport challenges. MSF thus began a pilot project to initiate eligible pregnant women on ART within two Khayelitsha MOUs in December 2004. This provided a fast-track system that streamlined services for providers and clients, and allowed late presenters to be initiated on ART within a week. Incorporating ART services within the ANC service was uncommon at the time, but it decreased loss to follow-up and limited delays by removing complex referral processes between facilities. Pregnant women with a CD4<sup>+</sup> count  $\leq 200$  cells/ $\mu$ l were fast-tracked for ART through weekly preparation visits, which included intensified adherence counselling and routine ART work-up. MSF trained and supported a midwife, an enrolled nurse, counsellors, and an outreach team of two obstetric medical officers provided by MSF and Mowbray Maternity Hospital (MMH).<sup>[7]</sup>

### Implementation of NIMART in pregnancy

There were a number of challenges associated with the provision of ART within MOUs, including staff shortages and turnover that required human resource planning and training. Visiting community obstetricians from MMH did not get involved in ART provision, as few were experienced in prescribing ART. The integration model demonstrated functional separation, as a vertical ART initiation service was provided by a medical officer in a separate room in the MOU on specific days of the week.

Midwife-managed ART initiation had been the objective of the integrated MOU model, but it took six years to achieve this, despite well-managed and effective nurse-driven ART services at adjoining ART clinics. Staff saw the provision of ART at the ANC consultation as an extra task to perform in an already busy service. However, a different approach was required when new national guidelines were released in 2010. The CD4<sup>+</sup> threshold for eligibility for ART was raised (to 350 cells/ $\mu$ l), thus increasing the proportion of women who qualified for ART in pregnancy. This required task shifting and extending the prescribing capacity of midwives from dual regimens to providing ART.

**'... NIMART is very interesting, in that it's not something you do as a midwife. It puts you on another level. You see a patient; you diagnose and manage them. This is not what I was doing in the labour ward. I learnt a lot – about HIV, the drugs, everything.'**

Following a successful pilot of nurse-driven ART in Lusikisiki and Lesotho, where there was a scarcity of doctors,<sup>[8]</sup> MSF partnered with the PGWC to implement a nurse-initiated management of ART (NIMART) mentorship programme in Khayelitsha in December 2011, with the first NIMART-trained midwives providing ART at the Site B MOU in May 2012. Early on, midwives were initiating 95% of clients within a week of first presentation.<sup>[9]</sup> There was strong support from midwives, and facility, programme and sub-district managers, and HIV integration and NIMART became policy. Midwives were excited by the NIMART training: 'For me, NIMART is very interesting, in that it's not something you do as a midwife. It puts you on another level. You see a patient; you diagnose and manage them. This is not what I was doing in the labour ward. I learnt a lot – about HIV, the drugs, everything.'

### Implementing Option B+ in Khayelitsha

The announcement on World AIDS Day in 2012 that South Africa would shift from Option A (AZT for women with a CD4<sup>+</sup> count  $>350$  cells/ $\mu$ l) to Option B (ART for all pregnant and breastfeeding women irrespective of CD4<sup>+</sup> count), highlighted the importance of NIMART mentorship for nurse midwives and ANC nurses. In July 2013, the Site B MOU in Khayelitsha implemented Option B+ (life-long ART for pregnant and breastfeeding women), including fixed-dose combinations, a new counselling model to support same-day initiation, and more attention to viral load (VL) monitoring in pregnancy, using VL as a predictor of transmission.

The rationale behind the introduction of Option B+ was not only to prevent the transmission of HIV to the infant, but to create an entry



point for lifelong ART care for women and their families. With this change, the linkage of HIV-exposed infants to care, retention in care for mothers receiving ART, as well as the provision of services which cater for male partners' needs have become even more of a priority. The implementation of Option B+ has been remarkably smooth. Since 1 July 2013, an average of 70 - 80 women have been initiated on ART monthly at the Site B MOU, and less than five women have refused to initiate treatment during this time. The fixed-dose combinations (FDCs) have made it easier for both staff and women. The adaptation of adherence counselling has led to shorter sessions that allow for same-day initiation, with increased post-initiation counselling being piloted in Khayelitsha. Despite the increased workload, midwives feel empowered and are passionate about their new role: 'Nowadays we manage their pregnancy and we also manage their HIV. I'm so committed that I don't care if I'm the one who leaves last – I don't mind. As long as I leave after seeing that every women who is eligible is initiated.'

The new challenge is to retain women on ART and achieve sustained virological suppression. An evaluation of the Option B+ programme is underway to study these outcomes. As more women who enter ANC services are already receiving ART (a quarter of the monthly new ANC attendees with HIV), an adapted model to prevent, detect and manage treatment failure is needed.

## Conclusion

A large part of the success of the PMTCT programme in Khayelitsha has been due to progressive provincial policies, and a successful partnership between the provincial and local authority health services, academic institutions and non-governmental organisations such as MSF and the TAC, as well as dedicated managers and staff. Khayelitsha is a severely disadvantaged and resource-limited area, and yet the PMTCT programme has remained at the forefront of innovation and has evolved in line with advances in global best practice in ART care. There is hope that in the not-too-distant future, paediatric HIV infection will become a disease of the past, read about in textbooks.

**Acknowledgements.** We thank the staff of the Site B MOU for their support in the compilation of this article.

**'Nowadays we manage their pregnancy and we also manage their HIV. I'm so committed that I don't care if I'm the one who leaves last – I don't mind. As long as I leave after seeing that every women who is eligible is initiated.'**

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## REFLECTIONS

# The secrets of the green and white cards

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It has been more than ten years now that we have been rolling out antiretrovirals (ARVs) to the general population. And we have achieved a lot. We have successfully initiated the world's largest ARV treatment programme in South Africa, and we are starting to see the positive impact of these efforts in indicators such as life expectancy and maternal deaths.

However, there is still much room for improvement. And I am not going to talk about the sometimes erratic drug supply in our system, nor about the fact that far too many patients still arrive at the hospitals' casualty departments with advanced disease, nor about the chronic deficits with regards to resources, including human resources. However, the missing improvement that many people do not consider is the lack of adjustment in our own practice of medicine. Have we, ourselves, as clinicians in 21st century South Africa, arrived at a point where we can sufficiently meet our patients' health needs? Have we, as senior clinicians and academic teachers, internalised the need for 'clinical literacy in HIV medicine' as a basic skill that we need to teach our young colleagues at medical schools and internship sites?

Yes, maybe sometimes we have. But far too often we are not meeting these needs. In my experience teaching clinical medicine, I routinely attempt to use the learning opportunity of ward rounds to sensitise junior colleagues to the value of the simple patient-held progress cards which are routinely used in public sector antiretroviral therapy (ART) and tuberculosis (TB) services across the country. With a number of such tools being utilised in our country by now, it is striking to see the differences in familiarity with such tools between our healthcare programmes. Clinicians are fairly comfortable with extracting the relevant information from antenatal booklets and from children's 'Road-to-Health-Cards', but the same is not true for the 'green' and 'white' cards that we are using in ART and TB services. Just in case you are not terribly familiar with the two patient-held treatment cards used in the public sector for TB and HIV patients, the 'white card' is the ART progress card, usually folded into one-third of an A4 size (and often further by the patient), while the 'green card' is the A5-sized two-paged TB treatment card.

Rather saddening, the same procedure repeats itself over and over again. During ward rounds, no matter whether in casualty, adult or maternity wards, a young eager colleague presents a patient as 'known HIV and TB patient, on treatment, now

admitted because of shortness of breath, diarrhoea, abdominal pains, etc.'. The standard conversation then continues as such:

Me: 'When was the patient started on treatment?'

Colleague: 'I don't know.'

Me: 'Did you look at the treatment cards?'

Colleague: 'The patient didn't bring them.'

Me, turning to the patient: 'Can you please give me the clinic card', when the patient usually grabs a plastic bag that is lying somewhere on his or her bed, containing some food supplies, money, possibly a handkerchief and the green/white cards.

What upsets me most about this exchange is not the 'taking chances' of our young colleagues – as a father of three I am used to such approaches, and after a busy night in the emergency department with multiple admissions, one probably has every reason to try to cut some corners. What really makes me sad is that we do not recognise the intrinsic value of these patient-held tools for our assessment and further management of the patient in front of us.

**'Have we, as senior clinicians and academic teachers, internalised the need for "clinical literacy in HIV medicine" as a basic skill that we need to teach our young colleagues at medical schools and internship sites?'**

More often than not, the TB and ART cards reveal scarring gaps in the clinical practice of these basic programmes. Patients are started on TB medication 'on clinical grounds', no sputum smear result is documented, or the intensive (four-drug) phase is ended and the continuation (two-drug) phase of pulmonary TB treatment is commenced without having confirmed sputum conversion in smear-positive cases. Similarly, HIV patients have been on 'failing regimens' for years, high viral loads were documented one to two years ago, but never followed up; worse even, single-drug substitutions have been performed in the presence of large, detectable viral loads.

Please do not get me wrong, I am not blaming the staff in our primary healthcare clinics for this – it is enough that they are often left alone in challenging supply chain settings, have no

clinical support or supervision, and have overwhelming expectations placed on them. As far as I am concerned, we need to pull up our socks as senior clinicians and academics. Yes, HIV treatment is today where TB treatment was a couple of years ago: it is largely governed by national protocols, has been handed over to primary healthcare clinics and is done by dedicated nursing staff in those facilities.

**'... we may not bother anymore to understand the basics of these programmatic treatments, as they may be perceived to be below our scope of practice. However, this attitude is going to cost us dearly ...'**

But as with TB, the 'handing-over' of HIV treatment to primary healthcare services bears a real risk in clinical practice: we as medical

doctors may not bother anymore to understand the basics of these programmatic treatments, as they may be perceived to be below our scope of practice. However, this attitude is going to cost us dearly as we sit on a national time-bomb of ever-increasing drug resistance in TB, and possibly soon in HIV, too. Nurse-initiation and management of ART is an essential, and incredibly valuable step in the broad rollout of ARVs. However, it must not result in us as medical professionals 'disempowering' ourselves in terms of clinical skills in treating these conditions.

In an attempt to address this growing trend, we recently reverted to the ultimate means an academic teacher has available to emphasise the importance of a topic we teach: including the interpretation of patient-held treatment progress cards into both the postgraduate and undergraduate examinations in Family Medicine. Inevitably, the results of the examinations were rather sobering this year. But now that it is no secret anymore that green cards and white cards may be in next year's examination ...

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## REFLECTIONS

# The Hannan Crusaid Treatment Centre – early beginnings and lessons learnt

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After 12 years, the Hannan Crusaid Treatment Centre (HCTC) in Gugulethu, Cape Town has screened more than 10 000 women, men, adolescents and children for life-saving antiretroviral therapy (ART). While we have seen a slow but steady increase in the starting CD4<sup>+</sup> count of new patients, the monthly inflow of new clients goes on unabated. A successful example of public-private partnership, this provincial clinic, supported by a local non-governmental organisation and initially funded by a UK-based charity, may provide a model for similar programmes within the National Health Insurance plan. Here we discuss the history and development of this programme, with a focus on lessons learnt about rolling out ART in South Africa more generally.

### Early beginnings

The first community-based treatment at the Gugulethu Day Hospital was provided in 2002 by a team from the Desmond Tutu HIV Centre, literally working out of a biscuit box! Dr Catherine Orrell, Sr Felicity Cope and six counsellors opened a clinic on three days a week, bringing in their daily supplies each time in a cardboard box and having to wait for the availability of a consultation room. The first patients were extremely ill and many did not survive the first few months of ART. Shortages of medication meant that rationing decisions had to be made on a daily basis. Despite this, the team continued with enthusiasm, as every patient was known by name, many received regular home visits, and some were at times escorted to hospitals by our doctors or had ART hand-delivered to them while in hospice care.

By March 2003, the ART service was able to open full-time with the addition of Dr Kwezi Matoti (and his room in the clinic, giving a dedicated space for the service), with Sr Lulu Mtswana heading *Sizophila*, a team of therapeutic counsellors who provided support for patients starting treatment. The first 150 carefully rationed treatment places were expanded to just 350, but we endeavoured to have an open-door policy – allowing people to attend whenever they felt they needed, and never turning anyone away. While the initial focus of the treatment programme was predominantly on the provision of ART in a primary healthcare setting, over time we also

established a strong research programme that enabled us to better understand the HIV epidemic and the impact of our interventions. Much of this work has gone on to inform local, national and international policies and, as elsewhere in South Africa, this demonstrates the potential synergies that academic medicine can bring to strengthening healthcare delivery. This has included insights into ART adherence, nurse-driven services to step-down ART management, earlier treatment of HIV/tuberculosis (TB) co-infection and rapid initiation of ART in pregnancy. Of note, the HCTC team helped to shape the first Western Province ART guidelines using the lessons learnt from this clinic, and these subsequently went on to inform the first national ART guidelines.



*In 2001, the size of the problem made it very clear that ART would need to be delivered at primary healthcare level and money was sought to provide such a programme in the Nyanga District of Cape Town. So began a three-way partnership between the Western Cape Provincial Department of Health, led by Dr Fareed Abdullah, the Desmond Tutu HIV Foundation and CRUSAID, the UK-based AIDS Charity with a large endowment from Ms Katy Hannan.*

### Lessons learnt

#### Adherence, loss to follow-up and virological failure

A strong interest in adherence led us to design our programme to include three treatment-preparedness sessions and to include pill counts at each visit. Early adherence data were excellent

and virological suppression (viral load (VL) <50 copies/ml) was noted in >90% of those receiving treatment at every time point in the first 3 years.<sup>[1]</sup> A system, initially called the 'red alert' system, was designed to identify and support those whose VL was unsuppressed (>1 000 copies/ml) at any point after starting ART. This 'red alert' system included an extra adherence-focused education session, an increased frequency of counsellor home visits, the provision of pill boxes and monthly visits to the clinic. We showed that 75% of those who experienced virological breakthrough could re-suppress their VL after this intervention.<sup>[2]</sup> Based on counting tablet returns, adherence appears to remain high in the cohort. Adherence continues to be an important focus of the programme and, with the introduction of TB treatment in the clinic in 2011, the adherence support system was expanded to provide integrated community support for HIV/TB co-infected patients.

### ***Sizophila* ('we are well') therapeutic counsellors**

In 1999, a small band of enthusiastic women who had survived HIV as participants in our early ART clinical trials stepped forward requesting to help others do the same. We taught them all we knew about ART, called them 'therapeutic counsellors' and initially asked them to work in our programmes at Somerset and Groote Schuur hospitals in Cape Town. These counsellors were the earliest accompanateurs or patient advocates and the forerunners of the community care

workers we have in our primary health programme today. Elaine Dube, one of the earliest and as passionate today, went on to become involved in the very successful antenatal care Mothers2mothers programme. Initially we started with a ratio of one therapeutic counsellor to every ten patients. Community-based, they worked in the areas where they lived, knew their 'assigned' patients personally, and were highly effective for many reasons: two important ones being their deep understanding of their condition and the impact of ART in their own lives, and the intense empathy that they offered, living openly with their own infection at a time when HIV was highly stigmatised. Today they remain the cornerstone of the success of the clinic and it is well accepted that any community-based ART programme requires community-based support.

### **HIV/TB co-infection**

Early on in the introduction of ART at HCTC, TB was recognised as the leading serious opportunistic disease, with more than half of patients receiving treatment for TB at the time that they started ART. This not only caused much suffering for affected patients, but patients with TB also had a doubled mortality risk compared with those without TB.<sup>[3]</sup>

However, the problem was compounded by the difficulty in diagnosing TB in patients with HIV. We found that only 25% of patients with sputum culture-positive pulmonary TB reported having a chronic cough for longer than 2 weeks. Moreover, we described

how sputum smear microscopy and chest X-rays are able to diagnose only a small fraction of the disease present; in turn, one-fifth of unselected patients not receiving TB treatment at the time of first enrolment in the clinic actually have sputum culture-positive TB, and this has led to much greater use of culture-based diagnosis.

Our studies have shown that patients who have HIV and TB face great challenges in receiving optimum and timely care when ART and TB treatment services are not integrated. In particular, ART is often unacceptably delayed. It has therefore been a huge step forward that, from 2011 onwards, patients have been able to receive TB treatment at the HCTC, and from 2012, multidrug-resistant (MDR)-TB patients have also been treated on site. We have further been able to show that increases in CD4<sup>+</sup> counts during ART are associated with major reductions in long-term TB risk.

### **Pregnancy**

Programmes for the prevention of mother-to-child transmission (PMTCT) of HIV were introduced at the Midwife Obstetric Unit (MOU) at the Gugulethu Community Health Clinic in 2001. With an antenatal care HIV prevalence rate of 29% in Gugulethu, pregnant women constituted a significant proportion of the patients who were eligible for ART. Work at the HCTC intensified to develop a 'fast track' system that would ensure a quicker route to ART commencement for pregnant and sick patients. In 2010, the Desmond Tutu HIV Foundation ran a pilot programme in partnership with the Western Cape Department of Health, demonstrating that it was safe, feasible and acceptable to initiate women whose CD4<sup>+</sup> counts were <350 cells/ $\mu$ l on the same day as their diagnosis during the first antenatal care visit, and that by doing so transmission rates could drop to as low as <1%.<sup>[4]</sup> This approach is now standard in the MOU as part of growing emphasis on providing rapid ART, and ongoing care and support to HIV-positive women during pregnancy and post partum.

### **Adolescents**

A review of the programme's outcomes confirmed what many first-world HIV programmes and other chronic disease clinical services were showing: that adolescents often experience a turbulent transitional developmental phase and may experience significant challenges in traditional ART programmes. Despite growing up in the clinic



*The Sizophila choir.*

**'... it is recognised that many of the adolescents are now growing into adulthood and from 2012 the clinic developed a Health Care Transition model to facilitate the shift from adolescent to adult services.'**

as model patients, older children often lose their VL control and find it difficult to adhere and attend services as they move into the teen years. In 2005, the HCTC recognised the need to be sensitive to adolescent needs, and organised patients aged 10 - 22 years into four age bands to attend clinic appointments in their specific age strata. These age-specific clinics were held in the afternoons with dedicated youth-oriented counsellors and a fun 'chill room' within the clinic. It is recognised that many of the adolescents are now growing into adulthood and from 2012 the clinic developed a Health Care Transition model to facilitate the shift from adolescent to adult services.

### The future

The HCTC was one of the pioneers of community-based ART in South Africa. The early provincial and national treatment protocols, as well as a score of subsequent policies and models, have emanated from this centre. The lessons learnt have been captured in peer-reviewed publications, which have in turn influenced the treatment programmes and policies, not only in South Africa, but in many treatment programmes throughout Africa and further afield.

The Centre has become an example of what can be achieved through a public-private-academic partnership whereby, via careful application of

a variety of resources – financial, logistical, expertise and innovation – in a climate of shared partnership and collaboration, much can be 'learnt by doing'. In a nationwide, public sector health intervention such as the South African ART programme, it is critical that specific facilities and services are maintained, where critical thinking, rigorous evaluation and innovation can be applied to ensure that, in an evolving and dynamic epidemic, the best health models and programmes are being utilised.

The HCTC has, over the last 12 years, not only screened over 10 000 women, men and children for the need for life-saving ART, it has in many ways reached much further to advocate for, instruct, change and improve the way in which antiretrovirals are administered on this continent and beyond. Importantly, this clinic – with its strong emphasis on patient education, patient support and mutual respect – epitomised the paradigm of the patient-centred approach that became the hallmark of HIV management. Our hope is that these lessons will continue to be learnt and written about as we enter the next decade in which we hope the flames of the HIV epidemic will be doused and we will see our patients growing older in good health.

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## REFLECTIONS

# What have we learnt from the last ten years of ART?

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The state programme giving free antiretrovirals (ARVs) started on 1 April 2004 in several large centres across South Africa. For many of us, it seemed unimaginable, after years of running HIV battles with President Thabo Mbeki and his odious Minister of Health, 'Manto' Tshabalala-Msimang, on everything from the cause of HIV to the efficacy of ARVs. A decade later, the state programme is the biggest in the world, with millions of lives saved and families returned back to normal life.

I was involved in the initial design of the programme, and have since been heavily involved in the implementation in rural and urban environments. I like to think about what I've learnt about HIV, and all the things I got wrong. Interestingly, seeing where we are in 2014, much of what has happened in the last decade was as unimaginable as the heady days of starting all those sick, desperate people on ARVs in 2004.

## Be ambitious

I remember Mark Heywood, the human rights crusader for Section 27, insisting that we put '80% antiretroviral coverage' when we wrote the 2nd National Strategic Plan, released at the end of 2006. The fractious paediatricians also insisted on ambitious prevention of mother-to-child transmission (PMTCT) targets. At the time, there were few places with >30% ARV coverage, and reports of poor antenatal PMTCT coverage were everywhere. I thought that they were being silly. By 2010, ARV coverage was close to 80%, and PMTCT transmission rates had fallen below 2%. Even when we designed the programme, in 2002 in dark rooms in the Birchwood Hotel, we continually asked whether drugs were affordable. Before we knew it, we had a pretty good first and second line, which were refined in 2010. Now we sit with a world-class fixed-dose combination and third-line drugs not even available in many developed countries, thanks to the decrease in cost. The Minister's crazy rush of blood to the head, where he wanted to test 20 million South Africans for HIV in one year in 2010, maybe took a few months longer than he had anticipated, but it got there – even though I thought it was impossible – and we're probably now the most tested nation on earth.

## We've taught chronic diseases a thing or two about adherence

I come from the typical physician world of diabetes, hypertension and asthma, where we hug patients who get >70% adherence.

The 90%-plus adherence demanded by ARVs seemed fanciful, until we tried it. Thanks to Médecins Sans Frontières (MSF) and the Treatment Action Campaign (TAC) and their adherence programmes, I've realised that meaningfully involving people in their care and making them understand their disease and how their drugs work, magically transforms them into prize adherence patients. I heard Prof. Steve Reid, a rural advocate, once say that he was amazed at how HIV patients could describe the lifecycle of the virus and evolution of resistance, while diabetic and hypertension patients, when asked what was wrong, would shrug and say: 'I have the high-high'.

## We may have saved the world from TB

If it wasn't for the HIV world seizing the tuberculosis (TB) research and policy agenda, we'd still be stuck with the gross lack of ambition that has left us with third-rate TB drugs and tenth-rate TB diagnostics for decades, couched in one of the most offensive and patronising public health programmes of all – 'DOTS' – while staring down the barrel of a growing multidrug resistance (MDR) nightmare. It staggered me that my patients in Hillbrow could permanently take ARVs 90% of the time, but the same patients had a <50% completion rate of six months of TB therapy at the TB clinic across the road. The story of how they came to the recommended dose of rifampicin (essentially 'what dose can we afford'), and my realisation that, far from what I was taught at med school, MDR was the fault of the programme (bad doses, poor support, poor understanding of the epidemiology), speaks volumes about the kind of history that TB has. It's become better. I still think the programme lacks some creativity and certainly resources, but at least we have a fighting chance, thanks to the increasing focus by clinicians and activists and their demand for integrated therapy and better drugs and diagnostics.

## We may have saved the world from old-fashioned public health specialists

Speaking of a lack of ambition, some of the most dispiriting conversations I have had have been with conventional public health specialists, saying that we were diverting resources from their sanitation/food/whatever programmes, with our 'non-sustainable' HIV programmes. Initially, I was defensive, until I realised how they had failed our continent on so many levels for decades – whether health promotion or disease prevention. HIV is common, serious, preventable and treatable, yet many did not seem to think

**'... he was amazed at how HIV patients could describe the lifecycle of the virus and evolution of resistance, while diabetic and hypertension patients, when asked what was wrong, would shrug and say: "I have the high-high".'**

it mattered. ARVs alone have increased life expectancy in South Africa by a decade, in just a few years, making it one of the most powerful public health interventions ever, right up there with good sanitation and vaccines. HIV care has driven energy and creativity into health delivery, and the focus on an evidence base has, at least somewhat, allowed us to question some of the holy cows of public health – from the design of healthcare delivery, the evidence for cancer screening, to obesity definitions and food recommendations – and this has meant a new and critical generation of people who can claim to have public health expertise. Now we routinely demand attention to evidence bases, human rights and patient demands from public health programmes, not always successfully it must be said, but a far cry from the kind of largely irrelevant public health I grew up studying.

### **Health system inertia may be our biggest challenge**

We sit with a health delivery system largely designed by European colonisers. They've moved on, but we have clung to a clinic-hospital, nurse-doctor model that was out of date 50 years ago. It is especially poor in dealing with an enlightened, google-empowered population asking hard questions of ill-prepared clinical services. Drug-delivery systems and training of health professionals seem constantly to be hamstrung by laws and rules generated by opaque bureaucracies within structures like the Health Professions Council of South Africa (HPCSA) and the Nursing Council – where it is very difficult to see which interest these structures serve. It seems we need massive re-engineering of the health system that goes well beyond what even the idealised National Health Insurance (NHI) looks like.

### **Attend many meetings and be patient**

One of my epiphanies of the last 15 years of working with the Department of Health (DoH) (it's true also in academia) is s/he who goes to the most meetings, wins. This is frustrating, but attention to process and keeping a beady eye on policy and choices, in an excitable field like HIV where there are many strident and powerful voices, is imperative. You can't rely on minutes and proxies; you've just got to make sure that you get on that Gautrain to Civicus Building with a fully charged iPad and lots of coffee.

### **We need a strong civil society more than ever**

For a while, we were all big buddies in the Zuma era. Government embraced activists and clinician groups. Post Manto, it was a breath of fresh air to be told how important we were. But we need to be careful – the defensiveness from prominent DoH members that followed the release of the drug stock-outs reported in December, including death threats and thuggish behaviour by security forces focused on TAC members in the Free State where the stock-outs were the worst, remind us of how prickly and unaccountable politicians and civil servants can be. We still do not have adequate explanation or closure on the bizarre Tara clamp issue, where a harmful device was used in the circumcision programmes in KwaZulu-Natal (KZN). Neliswa 'Peggy' Nkonyeni, ex-health minister

for KZN, instrumental in several superb KZN healthcare workers losing their jobs when she was Manto's quack foot soldier, is making a political comeback, and there are many people from Mbeki's cabinet who still seem to be successful, despite sitting quietly in his AIDS-denialist circle (c'mon Trevor, what *really* happened?). At a provincial level, patient advocates and concerned clinicians are routinely treated as optional extras or have their jobs threatened if they rock the boat in local AIDS councils. 'Protection' agencies such as the HPCSA continue to let Wouter Basson earn a handsome living while his victims' families live in poverty, while slapping down non-governmental organisations (NGOs) who support whistle-blowing with spurious appeals to privacy; the HPCSA and Nursing Council seem to think that it's better to let rural people die for want of healthcare, than license foreigners willing to work in places desperate for their skills. Civil society needs your money and your support, for all our future, to take on powerful vested interests.

### **The private sector, unions, churches and educational institutions have had a largely easy ride**

The excesses of the Mbeki era have allowed for many of these sectors to coast quietly on World AIDS Day platitudes and occasional HIV testing campaigns. I'm struck at Dr Jan Pienaar's aggressive nonsense HIV programme tackling new infections, stigma and fear at Anglo-American's Thermal Coal, and at the empty public statements from banks, shopping chains, universities, unions, major churches (in fairness, I've seen some amazing courage, especially from some Catholic groups), large NGOs, and opposition political parties. We need tangible commitments to testing and treating people, not the candle-lighting hand-wringing we all dread every 1 December.

I visited a very rural hospital in the Eastern Cape in late December – simply tarring the disastrous dirt road, now promised for years, would make ambulances accessible, health staff happier and prepared to stay, and allow for better support. The staff accommodation is appalling, and the hospital perennially grapples with understaffing. Not a single South African doctor works there. I was angry at how a middle-income country could let its citizens be neglected in this way. But the senior doctor working there spoke approvingly of the new district manager and how he was trying to get things going, about how she had got cooperation from the nurses by improving their living conditions, how the doctors were happier, and how successful the ARV programme was. We picked up a rural woman looking for a lift *en route* to the hospital, who spoke loudly and confidently about how she loved 'our hospital' (it was embarrassing that the doctor, who is from Europe, had to translate for me). A week later, back in civilisation, I bumped into a newly appointed senior member of the DoH who I've known and respected for years, who knew all the details of the hospital and the district manager, and rattled off ambitious plans for the next six months, expressing deep dismay at the previous maladministration. There is cause for hope.

We all have a stake in our DoH being as strong as it can be. There is a lot to be angry and concerned about, but it can't stop there. We have to continue to work constructively and critically, even if we are told we are not welcome at times. We need the protective institutions to be challenged, and we need to continue to strengthen civil society, even if it is just giving them much-needed cash. We need to keep re-imagining a better healthcare system. And we need to attend those long meetings.

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