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.