

University of KwaZulu-Natal, Durban

*Ronald Louw Memorial Campaign: 'Get Tested, Get Treated'*

Thursday 4 May 2006

**Forum Lecture: 'Normalising Testing - Normalising AIDS'\***

**by**

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\* I am indebted to Nathan Geffen and Marlise Richter for helpful comments but remain solely responsible for the contents.

1. I am honoured to be here and thank Prof Vasu Reddy, of the School of Anthropology, Gender and Historical Studies, and Ms Libby Collins, of the Student Counselling Centre, for inviting me to be part of this occasion.
2. Moving tributes to Ronald Louw have already been delivered, including by Zackie Achmat and Vasu Reddy.<sup>1</sup> Today I don't intend to deliver a tribute to Ronald, except by asking what sense we can make of his death. Why *did* Ronald Louw die? I am not speaking of physical cause. In the sense of fleshly fallibility, we know precisely what caused his death on Sunday 26 June 2005. He died of AIDS. Even though he was a well-nourished, fit, medically well-tended man, unencumbered by Africa's diseases of poverty, dislocation and deprivation, he died of AIDS. He died because his immune system, stricken by years of infiltration and assault from a single pathogen – the human immuno-deficiency virus – could no longer ward off rampant cumulative opportunistic infections that eventually exhausted his resistance and choked away his life.
3. Even though his life circumstances differed radically from those of most fellow Africans, in his death he shared a fate that has befallen and unhappily still portends for millions on this continent.
4. We also know that in Ronald's case, this outcome was preventable. He need not have died. The causes culminating in his death triumphed for a precise reason. He died not because help was unavailable, but because he accessed it too late. He was tested for and diagnosed with HIV on 15 May 2005 – the very day that he was admitted to hospital in Port Elizabeth with severe symptomatic effects of late-stage AIDS, barely seven weeks before he died.
5. AIDS is no longer a necessarily fatal condition. It is now a medically manageable disease. In many millions of cases throughout the world, it can be and is being successfully treated. Long-term survivors of AIDS are no longer a rare and unexplained exception – for those with access to treatment, they are the norm: Well over 90% of AIDS patients with access to anti-retroviral medication recover well from their illness and return to productive, re-energised living.
6. This Ronald knew. He knew the scientific facts about AIDS and its aetiology, and he knew the good news of its successful medical containment. He was deeply actively involved in both HIV prevention and treatment advocacy work, as

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<sup>1</sup> *Mail & Guardian* 11 July 2006 (Zackie Achmat), accessible at <http://www.aegis.com/news/dmg/2005/MG050701.html>; 'Dedication' to *Agenda* no 67, 2006 (Vasu Reddy).

provincial treasurer for the Treatment Action Campaign and as co-founder of the Durban Gay and Lesbian Community Centre. He had access to ample health insurance, and the promise of security and support from his friends and colleagues. Yet he avoided the medical devices of diagnosis until his body had already begun its final exhausted collapse.

7. How could this well-informed, politically conscious, sexually active, well-resourced man, highly informed about AIDS and infection by HIV and about his risk-exposure through same-sex experience, have died of AIDS? Why did he not test for HIV in good time? Why, when some years before his death, he suffered troubling lung ailments, that were strongly suggestive of AIDS-related complications, did he not agree to be tested? Why did he choose to remain undiagnosed when timely diagnosis offered a secure path to wellness? Why did he choose ignorance amidst the wealth of knowledge and knowledge-powered action available to him?
8. Ronald Louw did not die of ignorance or poverty. And, as a professor of law, a qualified attorney and an astute public interest tactician, he knew that, more than most in Africa, he would be protected from discrimination resulting from an AIDS or HIV diagnosis.
9. Surrounded by avenues of escape, Ronald Louw nevertheless died from AIDS. He died not of fear of discrimination or hostile treatment at the hands of his peers or his colleagues, or out of dread of others' reactions, but because of something more diffuse, more opaque, more difficult to diagnose and to confront. He died of a paralysing dread of confronting HIV that was located not in others, but within himself.
10. The enacted manifestation of stigma is discrimination and ostracism. There has been much writing and discussion and observation about the external dimensions of stigma in the AIDS epidemic. And there can indeed be no doubt that well-justified fear of discrimination and ostracism by others inhibits many people from choosing to be tested and treated.
11. But much less has been written and said about the internal dimension of stigma – the fear, self-disablement, feelings of contamination, self-rejection and self-loathing experienced by people with HIV, and those who fear they have HIV, even when they know that they will receive support, protection, treatment and acceptance.
12. Ronald Louw was I believe one of these. He died not because of external stigma, but because within himself there was a part that dreaded discovering that his body harboured a famous and famously reviled virus. That part was stronger than his cognitive appreciation of his friends' and colleagues' acceptance, stronger than his knowledge of the ready accessibility of treatment, and ultimately stronger than his ability to make life-saving choices for himself.
13. The most intractably puzzling part of stigma is not the part that lies in others. It is the part that lies within ourselves. It is more insidious, and more destructive, than external stigma, for it eludes the direct politically-conscious confrontation that we reserve for discrimination.
14. AIDS is often compared to tuberculosis, which, before treatment for it became widely available, was a highly stigmatised disease. Yet the comparisons with TB miss the point. AIDS is stigmatised not only because – like TB – it is associated with debilitation and death; it is reviled even amongst those who know that it is no longer associated with debilitation and death. This is no doubt because, unlike TB, HIV is in the great majority of cases sexually transmitted. But the important point is that the revulsion and fear is not only external: the external enactments of stigma all too often find allies deep within the person who has or

- fears infection with HIV. This leads to the inner shame and disempowerment that disable access to help, support, love and care. Ronald was I believe so disabled.
15. In *Witness to AIDS*, I try to grapple with this internal dimension of stigma, though I succeed only in taking what Jonny Steinberg perceptively called 'a gentle stab' at examining the question.<sup>2</sup> I speak of my own horror, in 1986, at discovering that I had HIV. Although working at a human rights public interest law centre at Wits University, surrounded by rights-conscious colleagues, so deep was my sense of self-revulsion that I could no more contemplate seeking their sympathy and support in the wake of my diagnosis than if I had molested one of their children or their domestic pets.
  16. I write of how the external stigma of AIDS – the fear of others' all-too-real adverse reactions – all too often finds an ally within: an ally that rejects health-affirming choices in favour of paralysed inaction, postponement, delay, denial and death. I suggest that we fail to understand stigma fully if we concentrate solely on its external manifestations and causes, and neglect the inner dimension that may be altogether more deadly.
  17. I write, also, of my Zimbabwean gardener, a quiet gentle man, who knew of the publicly-stated fact that I had survived AIDS because of access to treatment, and who knew also that I would secure access for him if he tested positive for HIV. Despite this knowledge, my gardener, while palpably wasting away from AIDS, repeatedly denied that he had HIV or that he was sick with anything more than TB, and ultimately went back to Zimbabwe to die what was by all accounts a lonely and medically unattended death.
  18. I tell the story in my book in self-reproach. The point I make is that I should have been more pro-active in ascertaining my gardener's HIV status; that I should not have left him to the isolation and loneliness of his own fears. I should have done more to insist that he be tested and diagnosed and treated. I should through my external actions have created a bridge for him to cross over the perilous rapids within that were preventing him from accessing medical diagnosis, care and treatment.
  19. This story has I think a wider point, for it is being played out throughout our region, and its wider point is directed at the human rights protections that we have erected around medical diagnosis of HIV.
  20. My book was published in early April 2005, six weeks before Ronald's diagnosis and his fatal illness. I know that he read the Zimbabwean gardener's story. On Monday 11 April, just days after my book appeared in the bookstores, he wrote to me, congratulating me on its appearance and saying how much he was enjoying reading it. With poignant meaning, Ronald relates that he had recently visited our mutual friend Zackie Achmat in Cape Town – Zackie had eighteen months previously started anti-retroviral treatment – and writes to me that he was 'pleased to see [Zackie's] progress to good health', as what Ronald dubbed 'a notable survivor': 'I'm sure', he added, 'he will continue engaging us for years and struggles to come'.
  21. Zackie is indeed so surviving, for he is on manifestly successful treatment. Yet Ronald did not. At the very time he was writing to me, he was barely a month away from himself collapsing, at his fatally ill mother's deathbed, with late-stage and ultimately irreversible AIDS. Most poignantly and significantly, when he wrote to me on Monday 11 April 2005, his HIV infection was still undiagnosed.
  22. This eloquent, informed, rights-conscious, duty-active, AIDS-literate man was writing to me from a pit of isolation and ignorance and fear, for, five weeks

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<sup>2</sup> Jonny Steinberg, 'Why do people allow themselves to die from stigma and fear?' *Business Day*, Monday, July 11 2005.

before his collapse and hospitalisation, he must have sensed that the symptoms of his fatal condition were pressing with mortal force on his health. He must have known, at some level, somewhere, that he was desperately and perhaps mortally ill. Yet he remained unable to take constructive action to elude the fate that so sombrely beckoned him.

23. There were in Ronald's case powerful additional reasons for his difficulty in confronting HIV. Pre-eminently there was his mother's long fatal illness and her imminent death. He was with her and tending her, immersed in her mortality, unable to deal with his own.
24. Yet amidst it all, the picture inerasably emerges of a man sophisticated in all the skills of this brutal and debilitating epidemic, except that of self-acceptance – and thus of self-preserving timely action.
25. My excursus on Ronald Louw's mental state is not intended as a mere deliberation on one heroic but isolated person's motive forces. Ronald's story has I believe urgent and compelling practical significance for us today. For Ronald's isolation and fear are by no means singular. From many communities, workplaces, churches, educational institutions there are similar reports – accounts of people who, like Ronald, have access to medication, support, and the assurance of acceptance and non-discrimination – yet who are too fearful, too tardy, to have themselves tested. These feelings have nothing to do with race, literacy, sophistication or book learning; they are too deeply human to be affected by the incidental specificities of social condition and education.
26. All too often the fears are grounded in external reality – and they are, regrettably, compounded by a government whose prevention and treatment messages are still not clear, single-voiced and unambivalent.
27. Yet today I ask us to reflect not on the reality of external stigma or the insufficiencies in government's response to the epidemic. I ask us to reflect on something those who consider themselves rights-conscious may find harder to face: the question whether the human rights protections we have helped erect around AIDS – and in particular its medical diagnosis – contribute to and reinforce the internal dimension of stigma.
28. I have suggested that the history of AIDS over the last 25 years can be seen as a struggle to assert the primacy of the material facts of physiology and virology in managing it over the damaging interposition of social conceptions of the disease.<sup>3</sup> If we treated AIDS purely as a physiological manifestation of its environmental and pathogenic causes – as we treat malaria or bilharzia – we would treat it merely as a 'normal' disease.
29. One of the aspects of the struggle to normalise it lies in the struggle to make the principles of medical management pre-eminent in the diagnosis and treatment of HIV. This has been represented in the struggle for the 'medicalisation' of the disease's clinical management, as opposed to its continued 'exceptionalisation'. In saying this we must acknowledge that the public health debates and campaigns that the epidemic sparked have led to considerable reconfiguration of disease and patient management (for instance, in giving patients more agency and autonomy, in ensuring that patients understand their diseases and that they meet their doctors as partners, not as subservient recipients of care). In urging the normalisation of AIDS, one therefore concedes that the exceptionalisation of AIDS has beneficially influenced what we now consider to be 'normal' for all diseases.

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<sup>3</sup> Stellenbosch lecture Wednesday 12 October 2005, *Stellenbosch Law Review*, accessible at [http://law.sun.ac.za/judgecameron\\_lecture.pdf](http://law.sun.ac.za/judgecameron_lecture.pdf).

30. But still we remain very far from treating AIDS as just an ordinary disease. And the question I raise is whether the continued exceptionalisation of AIDS from the human rights point of view is not undermining human rights. Ronald's death shows us that the struggle to normalise AIDS is not just against stigma's external manifestation, but against its internalisation in those who have, or fear they have, HIV – the shame and disempowerment and self-disabling ignominy they all too often feel.
31. And this forces us to ask whether the medical protocols and procedures that surround diagnosis with HIV and treatment for AIDS reinforce the internal manifestation of stigma and thus impede access to treatment.
32. For 25 years, by widespread (though not universal) consensus among public health specialists, AIDS has been treated as exceptional. The consensus arose mainly because of the enormous stigma attending AIDS, and the fact that there was no treatment for it. Additional considerations included the long latency period of the virus, and the fact that it was mostly transmitted during intimate consensual conduct between adults in private. In addition, although HIV is infectious, it is a weak pathogen which is not easily transmitted. And detection of HIV infection in its early stages is not always easy.
33. For all these reasons, the AIDS epidemic was treated in ways that differed signally from previous public health emergencies. At the core of this approach was the well-known 'AIDS paradox': the recognition that protecting the rights of those with HIV was not inimical, but complementary, to containing the disease. Coercive measures were recognised as not just needlessly punitive: they put the very public they were designed to protect at unnecessary risk of further infection by driving people away from diagnosis and counselling for behaviour change.
34. But this paradox has led to a further paradox. One of the ways in which people with HIV were protected was by hedging diagnostic procedures in the healthcare setting with elaborate special measures to ensure confidentiality and knowledge and consent.
35. Consent to HIV testing could not be general: it had to be specific. And it could not be tacit: it had to be express. And the momentous implications of diagnosis had to be carefully canvassed with the patient both before and after the test in carefully constructed counselling sessions.
36. These protections treated the disease as exceptional, because it was exceptional – not only because of the level of stigma that surrounded it, but because no medical treatment was available for it.
37. But the world has changed. And the epidemic has changed. The protections were designed for a world in which stigma caused death, and in which protection from its effects could often be secured only by protecting the patient from unnecessary HIV testing, whose only product, all too often, was victimisation, ostracism and discrimination.
38. They were designed for a world in which, while the opportunistic infections associated with HIV could be palliated, little could be done to halt the inevitable assignment with death that infection entailed.
39. All that has changed. Because of the activists' struggle for the normalisation of AIDS – including that of the Treatment Action Campaign in our own country – treatment is now widely available. Even in many desperately resource-deprived settings, anti-retroviral treatment is becoming more and more accessible.
40. And where treatment is available, signs increasingly suggest that the exceptionalisation of HIV infection in the healthcare setting may be impeding its effective management.
41. This is because many people, offered the choice of diagnostic procedures whose exceptional and unusual nature is emphasised, prefer not to be tested. When

they visit a healthcare facility, they are not simply and merely tested for HIV. The diagnosis of the disease is treated as exceptional, and is hedged around with fuss and palaver and hullabaloo, including the requirement of express and specific consent, and the insistence on pre-test counselling.

42. These safeguards are intended for the protection of people with HIV; but today I suggest that they also serve to reinforce the inner fears and dread – the inner sense of self-contamination – of those who suspect they may have HIV. All too often those safeguards accentuate the inner disavowal of entitlement to betterment. People shy away from being tested because the requirements relating to consent and counselling accentuate the differentness and distinctness and horror of AIDS. They emphasise to the patient that this disease is exceptional, abnormal, unusual.
43. As a result, rather than consenting to being tested, many shy away. They prefer to ascribe their symptoms to causes other than HIV, when all too often the routine administration of a test will confirm the opposite, and will open the way to effective management of their condition.
44. Where effective medical management of the disease can be offered to patients, this suggests a new and disquieting paradox: that the exceptionalisation of HIV, designed to protect from needless discrimination, may constitute a barrier to diagnosis and treatment.
45. This in my view it requires us to reconsider urgently the exceptional protections for HIV testing in the healthcare setting and to ask whether they should be relaxed.
46. Undoubtedly, a patient should only very rarely be coerced into a diagnostic procedure against her or his will. This principle is particularly important where the likely consequence of diagnosis continues to be ostracism, discrimination and isolation.
47. But where diagnosis could lead to treatment, to the preservation of the patient's life – and where continued ignorance will surely hasten death – the healthcarer's duty of beneficence to the patient demands that accurate, early diagnosis of the treatable condition should be encouraged. Where possible, diagnosis should be a routine and uncontroversial element in the patient management process.
48. Where treatment is available, the aim should therefore be to make HIV testing normal, and not abnormal; and the exceptional procedures and barriers surrounding it should be diminished and if possible eliminated.
49. Within this debate lies a logical and conceptual issue at the heart of the struggle for the normalisation of AIDS. In what sense can we reliably claim that the disease is special? Nothing about AIDS – the disease itself, or the epidemic – is intrinsically exceptional. Its exceptional features (the extent of the pandemic; its destructive impact; the stigma surrounding it; the discrimination) are purely contingent, and the exceptional responses to it accordingly purely strategic.
50. In principle, therefore, our strategic responses to AIDS should be aimed at normalising the treatment of HIV, not only socially, but more urgently within the healthcare setting.
51. The exceptionalisation of AIDS, which was designed to protect those with HIV, now constitutes a source of risk and harm. The fuss and bother that surrounds HIV testing in healthcare settings where treatment is available constitutes an additional source of fear and inhibition for those with HIV and those who fear they have it, and reinforces their own conception of the exceptional, horrific and unacceptable nature of the infection.
52. Ronald Louw's story, and its repetition in countless similar tales in this epidemic of prejudice and ignorance and fear, illustrates the risk. Normalisation of AIDS, and normalisation of testing protocols around it, may well have led to his earlier

diagnosis, since the medical personnel attending him would have been less inhibited about encouraging and even urging him to take the test. If, when he sought medical management of his lung infections some years before his death, Ronald's consent to testing had been taken as implicit, the later effects of HIV on his body could have been easily contained.

53. The meaning of Ronald Louw's death lies in its warning to us that where treatment is offered to the patient, testing protocols, though designed for protection, may be colluding with the patient's inner fear and denial, with all too often fatal consequences.
54. Let me be quite clear about what I am advocating. I am suggesting that where three conditions exist, we should re-medicalise the diagnosis of HIV, by making it a normal part of medical treatment, subject only to a patient's deliberate and express refusal to be tested. Those conditions are that
  - anti-retroviral treatment must be available for offer to the patient;
  - there must be assurance that the consequence of diagnosis will not be discrimination and ostracism; and
  - the patient must be secure in the confidentiality of the testing procedure and its outcome.
55. Those conditions are still rare in Africa. But where they do exist, we must move urgently to normalise the treatment and diagnosis of AIDS. They existed for Ronald, and had normal beneficent medical procedures been applied in his case – instead of the inhibited disclaimers, prohibitions and disincentives to HIV testing – his disease would in all likelihood have been diagnosed sufficiently early for his death to be avoided.
56. Let me be even clearer. I am advocating that where treatment, non-discrimination and confidentiality can be assured, we should even forgo insistence on pre-diagnostic counselling. In saying so, I acknowledge that pre-test counselling exists not merely to satisfy human rights concerns. There is evidence that well-structured and -administered pre-test counselling reduces risky sexual behaviour (whether the test subsequently shows negative or positive).
57. Pre-test counselling (perhaps even in the form of HIV treatment literacy workshops) is therefore desirable and useful. There is also evidence that post-test counselling is useful and important. Counselling is therefore useful *provided* that a health care facility is able to offer it without sacrificing the time and energy of its healthcare personnel. That time is urgently required for diagnosis and treatment of HIV.
58. But where pre- or post-test counselling drains healthcare resources away from diagnosis and treatment of HIV, we must now acknowledge that it constitutes an impediment to the effective management of the disease. We must acknowledge that it is costing lives.
59. It is true that AIDS is a dread disease, and that pre-test counselling assists those with it to adjust to their condition. But malaria, cancer and insulin-dependent diabetes are also dread, potentially fatal, diseases – yet no testing or counselling protocols inhibit their diagnosis and effective management.
60. In a mass epidemic of HIV, where mass treatment is now be a realisable fact, pre-test counselling may be a luxury we can no longer afford. Our commitment to normalising AIDS must now include a commitment to equate its medical diagnosis and management with that of other treatable dread conditions.
61. Had we realised this earlier, we may have helped saved many lives, including that of Ronald Louw. This week's campaign – *GET TESTED, GET TREATED* – is therefore our most potent tribute to Ronald: and it asks us all – especially those of us who consider ourselves human rights advocates – to explore its implications without flinching.