

# Ethical dilemmas in an antiretroviral clinic – a narrative

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It is Monday morning and a small health care team prepare to face the realities of another day in the antiretroviral clinic. One doctor, 4 nursing sisters and 1 pharmacist are on duty and 80 patients have been booked for the day. They know that at least 10 more patients will arrive unbooked because they are too ill to wait for their appointment date. Everyone works beyond capacity; yet, the waiting list is stretching out 4 months ahead. Many of these patients will never make it to the clinic.

This is not an unusual story. Around 6 million South Africans are living with HIV/AIDS. HIV kills at least 370 000 of us each year.<sup>1</sup> Between 500 000 and 1.4 million South Africans are in immediate need of antiretroviral treatment. Less than 1% of them are on treatment.<sup>2</sup> How do we as health care workers respond to such immense incongruity and such desperate need? The question no longer is whether we need to treat this devastating disease, but rather who we need to treat and where we need to treat them. This article addresses the ethical predicaments surrounding each of these questions.

## WHO DO WE TREAT?

### Futility and fallibility

The waiting list at our clinic makes the question of who we need to focus our efforts on explicit. Should we prioritise the most desperately ill or rather focus on the patients with higher CD4 counts, who have a better prognosis? The issue seems straightforward: we have limited time, fiscal and human resources and we need to utilise these as rationally and effectively as possible.

*A few patients have been sitting in the cold outside the door of the clinic since 6 am. They hope that their early rise will spare them the long queues. The first patient to be seen is 23-year-old Lettie.\* She is carried in on a stretcher by hospice staff. Her family left her there 2 weeks ago to die. She has World Health Organization (WHO) stage 4 disease with cachexia, oral and oesophageal candida, and AIDS dementia complex. Lettie appears terminal and I fear that she has reached us too late. Starting antiretrovirals goes against all the national*

\* Pseudonym

*guidelines. Lettie is unaware of her HIV status and unable to communicate, and can therefore not consent to treatment. She has no family support system, and cannot even swallow the tablets. Furthermore, her body weight is 30 kg and her CD4 count 35 – the toxicity of the drugs will surely overwhelm her fragile system. Her caregivers however plead with us and after some lengthy deliberation among the doctors, sisters, social worker and dietician it is decided to attempt a trial of treatment. After careful explanation of all the medication, the hospice staff leave with Lettie and leave me with a feeling of trepidation. Three trying months later, Lettie walks into my consultation room: she is still a little unstable on her feet, but can walk unaided. She has gained 21 kg, has lost all traces of AIDS dementia, communicates well and is back at work. She is a lovely, articulate woman with a will to live.*

Lettie's case, and other similar ones, have thrown our tentative attempts at risk-stratifying patients into disarray. Lettie serves as a living example of the dichotomy of the fragility and immense strength of the human body, and also the fallibility of our judgements. She reminds us that, on the boundary of life and death, we are working outside the traditional precepts governing futility judgements. Our provisional and uncertain knowledge demands that we obey the duties of beneficence and non-maleficence, and cultivate the virtues of fidelity, courage, compassion and discernment.

There is no logical and simple manner in which to apply the principle of distributive justice in this resource-limited setting. I argue that by disregarding those who are the worst off, we are imposing on them a second injustice. They have already been discriminated against by virtue of their socioeconomic status, reflected in their lack of information about the disease and its prevention, stigmatisation and lack of accessible and timely treatment. To deny these patients treatment at the end of their disease would be a gross injustice. A just society owes it to those who are the worst off to have some chance at recompense. We cannot deny these desperate patients hope and treatment even if it places a higher burden on society.

Where does this leave patients who are not yet desperately ill? The South African national treatment guidelines state that

patients with WHO stage 4 disease or a CD4 count < 200 are entitled to antiretrovirals. These eligibility criteria embody a rationing principle that has become a moral quandary.

*Thabane\* is a 32-year-old mother of two. Her husband died last year, presumably owing to AIDS. Thabane has a CD4 count of 310, has no signs of opportunistic infections and is working and supporting an extended family of five. Her immunity is dwindling and she is facing an increasing risk of tuberculosis, yet she does not qualify for antiretroviral treatment. She is still too well. Clara\* is 30 years old and is severely ill: she has a CD4 count of 0, a viral load of 1 000 000, a haemoglobin level of 5.6 g/dl, a chronic cough and chronic diarrhoea. She is started on treatment and develops reconstitution syndrome with pulmonary tuberculosis, hepatosplenomegaly, portal hypertension, lactic acidosis and a plummeting haemoglobin in the first month. She is admitted to a tertiary care facility twice, but no further investigations are performed as her prognosis is so poor. Clara is transfused, rehydrated and sent home and will undoubtedly arrive at the clinic in a week's time with severe anaemia, electrolyte disturbances and perhaps by then also renal failure.*

As with Lettie, I believe Clara should be investigated and treated as fully as possible. Yet, to exclude Thabane from treatment because she is still well might in time prove to be imprudent. It has been argued that patients with higher CD4 counts are denied the potentially greater benefit in order to give a lesser benefit to others who are more urgently ill. Is this an irreducible dilemma? Can we stretch our resources to cater for the less urgently ill or are we doomed to remain a decade behind the pandemic and forever in crisis management?

### Are all created equal?

To complicate the issue of distribution of resources further, it has been suggested that people with vital or scarce skills, such as teachers and doctors, should receive priority treatment, or we might be left without sufficient teachers to

educate the nation and health care professionals to provide antiretroviral services. Similarly, Daniels<sup>3</sup> notes that some groups may be viewed as more deserving of treatment. For example, people who are infected by contaminated blood, or who are rape victims, might be thought to be owed some special compensation because they are the victims of social neglect or negligence as they were deprived of a basic human right such as security of the person. Choosing the 'more deserving' would however propagate the sentiment that all people are not as equal as our constitution proclaims and further fuel the stigma of individual blame and guilt.

Farmer<sup>4</sup> reminds us that dominant forms of disease causality in individuals tend to obscure the complex interaction between equity and health. HIV is not merely a pathogen, it is also a social disease and the complex interaction between exposure and vulnerability is also a consequence of the existing social, structural and environmental conditions in which we are living. This disease is fundamentally enmeshed in human judgements and decisions of value. Individual definable risk leads to blame and stigmatisation, and hence sensitivity towards the embedded social dynamics, especially of the most vulnerable and marginalised, is needed in order to effect just and equal treatment for all.<sup>5</sup>

### Judging people

The national guidelines emphasise compliance to treatment, not only because of better outcomes for individual patients, but also for fear of the emergence of multidrug-resistant strains that may pose a significant public health risk. Although there is very little empirical evidence for this fear, the disastrous implications thereof have been prohibitive and persuasive. Therefore, the guidelines are based on both assuring best outcome and avoiding the worst case scenario.<sup>3</sup> Increased compliance has been linked with psychosocial readiness, such as open disclosure of HIV status, a family support system, a fixed residential address, lack of substance abuse<sup>6</sup>

and regular clinic attendance. Are these requirements merely medical eligibility criteria, or do they embody implicit value judgements? These criteria eerily remind of the American 'God committee', infamous for basing judgements for patients' eligibility for renal dialysis on patient desert and contribution – for instance, church attendance and a number of family dependents. In South Africa, patients who have no family support system because of AIDS-related deaths, violence or other social misfortune will be excluded from the programme, once again imposing on them a second injustice.

### A meeting of minds

A challenge that has become one of the most complex in our clinic has been that of traditional healers and so-called traditional medicine. The WHO estimates that 80% of African populations consult traditional healers,<sup>7</sup> yet there is a dearth of reliable research into this area of medicine. There is anecdotal and early scientific evidence warning of significant interactions between traditional and Western<sup>1</sup> medicine (I use these politically loaded terms at face value and for the sake of brevity, and do not underscore them with the sociopolitical and power relations attributed to them). This has raised the question of whether patients using traditional medicine should be excluded from the antiretroviral programme.

*Mary\* was doing very well on antiretrovirals. After 6 months on treatment her CD4 count had risen from 40 to 209 and her viral load was undetectable. She was now out of the initial danger period and all seemed set for an ongoing, good clinical response. At the 7-month visit, Mary started complaining of painful swelling of her legs. Apart from mild pre-tibial oedema, further clinical examination and blood investigations (full blood count, liver function test; urea creatinine and electrolytes, and lactate) were completely normal and she was given a follow-up appointment in 1 week. The next week she had massive oedema of*

both legs with blood-filled blisters and deep ulcerations. She was admitted and once again all further investigations were normal. Mary passed away the following day, leaving us shocked and perplexed about her sudden deterioration. A family member visited us after the funeral and explained that the family had taken Mary to a traditional healer because they did not want her to continue with our 'toxic' medicine. Mary had refused, but eventually relented because of ongoing family pressure. The traditional healer started treating her with an unknown cocktail of substances 1 week before her sudden onset of new symptoms.

Could traditional medicine have caused Mary's symptoms and early death? We know that proximity in time and space does not prove causality; yet, in the absence of solid evidence, we are plagued by the suspicion that a fatal drug interaction claimed Mary's life. Can our suspicion, fear and ignorance therefore preclude traditional practices from the antiretroviral programme? Traditional healers embrace a broader view of disease causality and treatment, incorporating concepts of community, interpersonal relatedness and social origins of disease, and can therefore make a valuable contribution to the management of this multifaceted illness. They play a key role in community care-seeking behaviour and I would call for the formal health system to welcome them into a network of treatment where tradition can be used to strengthen referral, counselling and support services. It would appear as if the formation of the 'traditional indigenous knowledge' arm of the MRC is a step towards realising this goal.

#### WHERE DO WE TREAT?

In South Africa initial government ARV treatment sites have been located in urban settings within existing hospitals, often tertiary care facilities, where diagnostic and treatment equipment and trained personnel already exist. With regard to efficiency – reaching a large number of patients in a short time – this makes sense. However, will such a

programme simply serve to replicate the existing inequities in terms of national resource allocation, as is evident from the unequal distribution of both health care facilities and personnel? Such a plan risks leaving rural areas and groups with traditional vulnerabilities inherited from the discrimination enacted in the past, entrenched in their existing inequity.

David McCoy<sup>8</sup> has argued compellingly that emphasis should be placed on distributional equity. He reasons that the opportunity now presented by the influx of donor money into Africa should be maximised by moving the health care system as a whole toward an equitable and sustainable distribution of care. 'Instead of focusing on the most resource-rich sites and areas, a special effort should be made to make the "3 by 5" and other programmes reach out to rural and other underserved populations from the beginning, putting the resources necessary into training and infrastructure that can later mean better health for traditionally underserved populations. 'This sentiment is strengthened by Coovadia<sup>9</sup> who says that as long as people's basic needs remain unmet, they cannot garner the resources to fight HIV.

Training and ongoing support of patients and health care teams in all settings become paramount as ongoing treatment compliance and physician skill have been shown to be one of the greatest determinants of treatment success. Our primary health care facilities clearly need to be up-scaled in a dramatic fashion and staffed with experienced and enthusiastic teams if we want to fulfil our vision of equitable and sustainable delivery of antiretroviral services.

#### CONCLUSION

The HIV pandemic continues on its devastating rampage and we have been found lacking in our efforts to contain it. Our nation's efforts have been characterised by denial, poor leadership, and a slow response to treatment action. Our national treatment

guidelines are worryingly silent on the heart-rending ethical challenges health care workers face every day. But we should not be too harsh in our judgements: HIV is redefining the concepts of ethics, responsibility and justice. On a global scale it has raised moral concerns of social justice with regard to access to health care, basic human rights, government's responsibility to care for its citizens and effect a just society, and the duty of beneficence of the developed towards the developing world. On a national level it has opened the debate to reconceive issues of distributive justice, fairness and desert. HIV has firmly focused the spotlight on what we as a society do collectively to manage this pandemic in a responsible, sustainable and equitable manner. In the words of Mandela: 'History will judge us harshly if we fail to do so now, and right now.'

References available on request.

#### IN A NUTSHELL

The current main ethical issues around antiretrovirals are who to treat and where to treat them. Current treatment guidelines are insufficient to address these ethical issues.

There is a lack of adequate funding, distribution and 'roll-out' of antiretroviral clinics.

In South Africa, less than 1% of people in need of antiretrovirals have been started on treatment.

Denying treatment to patients with a bad prognosis would be a second injustice.

An exclusive focus on determinants of compliance may embody implicit value judgements.

Traditional healers should be incorporated into the formal health care network.

Placing antiretroviral clinics within the existing health care system would entrench existing inequities in health.