Letters

End-of-Life Decisions

To the Editor: The CPD article titled *Voluntary active euthanasia: Is there place for it in modern day medicine?* is strong on definitions but does finally point out how the debate leaves out "the good of the patient who wishes to die".[1] It is the way that "good" is understood that is a particular concern of family-medicine practitioners who aim to amplify the meaning of patient-centredness. It is, by the way, the kind of concern that finds shameful the argument that "in South Africa we have much more important issues to attend to".[2]

The authors aim to open up a debate that has stagnated in South Africa. I recently resorted to the *SAMJ* to discover what had happened to the South African Law Commission's Report 86 and the Draft Bill with the short title of *End of Life Decisions Act 1999*.[3] I wrote that an outstanding feature of the Report was its survey of worldwide debate and legislation that had made so much progress in many countries and its excellent overview and discussion of end-of-life decision making. I remain none the wiser.

Your related editorial suggests that "the topic is still open for more legal and ethical discussion before some form of consensus is reached". The debate has indeed been so conflicting and polarised that, in my opinion, consensus *before* legislation is unlikely. It was striking how the South African Law Commission argued that it was inappropriate for legislature to seek to balance religious views in a pluralist society.
I want to draw attention to how the debate has, however, continued internationally. This debate is not reflected in the CPD article's references, the last of which is dated 2003. The most dramatic contribution to progress in this matter comes from Belgium and is titled *Development of palliative care and legislation of euthanasia: antagonism or synergy?*[4] I have to be content only to quote from it:

> *Although palliative care and legalised euthanasia are both based on the medical and ethical values of patient autonomy and caregiver beneficence and non-malificence, they are often viewed as antagonistic causes. A popular perception, for instance, is that palliative care is the province of religiously motivated people and the advocacy of euthanasia that of agnostics or atheists . . . Advocates of legislation always supported palliative care and never presented euthanasia as an alternative . . . From the start shared staff ensured connection between palliative care and euthanasia and urged linking their objectives. These joint efforts came to be described as 'integral palliative care'. As the societal debate about euthanasia grew, so did provisions for palliative care.*

The Flemish Palliative Care Federation adopted an explicitly pluralistic stance. It stated that "Palliative care and euthanasia are neither alternatives nor antagonistic". The discussion concluded as follows: "Within Belgium we found . . . no evidence that the drive to legalise euthanasia would interfere with the development of palliative care. Rather, there were many indications of reciprocity and synergistic evolution."

It is important to be sure that such progress is no longer hindered by the "slippery slope" argument – that permissive legislation would result in physician-assisted death becoming more common over time among so-called vulnerable patients, such as the elderly. The question was well reviewed in an editorial in the *BMJ*, which reported that an analysis of databases from Oregon and the Netherlands found no such increased incidence of physician-assisted death, with the one exception being applicable to people with Aids.[5]

The 2005 study in the Netherlands by Van der Heinde et al concluded that the Dutch Euthanasia Act had been followed by a modest decrease in the rates of physician assistance in dying.[6] It is also important to know that similarly detailed and thoughtful studies in Belgium, which explored many aspects of physician behaviour in this context, found increased carefulness in decision making and that end-of-life decisions were discussed more often with patients, relatives and nurses.[7]

These accounts show how the consensus impasse can be transformed and how permissive legislation actually *improved* end-of-life decision making. May the South African Law Commission's nine-year-old contribution to such legislation be revived and the advance of the disciplines and practice of modern palliative care be prioritised, especially because of the prevalence of HIV/Aids.

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Letters

The Reality of Order and Chaos

To the Editor: Dr Chris Ellis's wonderfully poetic article on Chaos Based Medicine[1] got me thinking about Traditional Chinese Medicine (TCM) again. Yin and Yang are the two pillars of TCM. Everything in Chinese Medicine has a Yin and Yang pole to it. Poles are not parts but belong together, and Yin and Yang are in a dynamic relationship to each other. This may not make much sense to Westerners until one explains that the Yin pole can also be interpreted as order and the Yang pole as change. So in all seemingly-isolated systems there is both a Yin (order) and a Yang (change) functioning pole. Order is the window through which science peers (evidence-based medicine) in order to understand the world around us, and change (chaos medicine) is the dynamics referred to by Dr Ellis.

If we understand the limitations of evidence-based medicine, family medicine as pointed out by Dr Ellis really does interface a world in which the order/change dynamics find a more comfortable place to operate in. Science is an attempt to understand the change/chaos complexity from its vantage point. There are serious limits however to what can be measured by science.[2] Weather forecasting remains a forecast despite all the satellites and statistics. Scientists are unable to measure both the wave properties and particle properties of light at the same time and the butterfly effect points to the fact that small input can have profound effects, confusing all our rational and linear dialogue with the world around us.

This should not really surprise any of us. The concept of order/change is itself an attempt to make sense of a world that at its very foundation is not order or change but a wonderful, surprising and forever great mystery in which order and change are merely words like weather prediction to map the impossible. Complexity which is the real world which contains order/change dynamics cannot be understood by measuring what appears to be order for the simple reason that the non-visible, immeasurable and non-linear will continue to confound what appears as order to our scientific mind.

“Complex systems – both chaotic and orderly – are ultimately unanalysable, irreducible into parts, because the parts are constantly being folded into each other by iterations and feedback.”[3]

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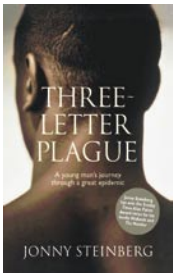
Book Review



Three-letter plague: A young man’s journey through a great epidemic

By Jonny Steinberg

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Johannesburg, in 2008
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Book price: R170

To the Editor: The book is set in the Lusikisiki area of the Eastern Cape, where Jonny Steinberg enters the world and world view of a man called Sizwe in a remote rural village, who has made a business of the local spaza shop. Médecins Sans Frontières (MSF) has come to Lusikisiki to demonstrate to the government and department of health that a successful anti-retroviral (ARV) treatment programme could be run by nurses in rural clinics. In the story, Dr Herman Reuter is the epitome of MSF’s no-holds-barred approach to establishing the programme.

The picture that formed in my mind as I read the book was that better health for this community was a complex interaction between, on the one hand, uncompromising commitment to better *quality of care,* and, on the other, decision making based on the perceived implications for one’s *quality of life*. Surprisingly maybe, for the medical profession, the two perspectives do not necessarily see eye to eye.

As the reader gains insight into main character Sizwe’s perspective on HIV, MSF comes to Lusikisiki and transforms the health service. The quality of care is almost relentlessly improved in terms of the electrification of clinics, the employment of additional staff, the provision of medication, the reduction of waiting times and community outreach. The philosophy is one of making ARVs available in the smallest clinics and relying on a network of community activists, counsellors and nurses to make testing acceptable and treatment accessible. Hundreds of people come for testing and people at death’s door have their lives renewed through taking ARVs.

The counterpoint to this remarkable success story is a man who refuses to be tested for HIV. The book reveals that this decision is ultimately not one made out of ignorance or a medically non-compliant attitude, but one made out of ambivalence and regard for the impact testing could have on the quality of his life. Sizwe is a big fish in a small pond and his success at establishing a spaza shop business leads to his fearing that he may attract a backlash of envy and jealousy. His financial success, however, opens up the possibility of a traditional marriage, by which his children would be recognised heirs and part of his cultural lineage. At the core of his ambivalence about testing lies the fear that he would not be able to realise this dream if he tested positive, since the guilt, shame and stigma associated with being HIV positive would make it impossible. Testing therefore may destroy his quality of life.

Surrounding him in his ambivalence is a swirl of beliefs and concerns in his community regarding the MSF programme. People suspect that HIV may have been created by white people to subjugate the black population after 1994. People even suspect that the lubrication of condoms and the actual test itself may be transferring the disease to the community. There are rumours of traditional medicines that, unlike ARVs, can cure and not just repress the virus. Those who go for testing are closely watched, and the length of time spent being counselled is considered an indication of their status.

While one cannot generalise from one man’s perspective, the in-depth exploration of Sizwe’s ambivalence reminds us that there is not a direct linear relationship between quality of care and health outcomes. A high quality of care may be necessary, but not always sufficient. We are also reminded not to add more judgement, shame and guilt to people struggling with their ambivalence and cultural context to make important decisions. Decisions are not merely a weighing up of medical information, but a balancing of implications and priorities for one’s whole life.

This book caused me to reflect and once again consider my role as a doctor in the midst of the Aids pandemic. I would recommend this well-written book to all health workers as a reminder and vivid example of our need to pursue quality of care and, at the same time, be holistic and gentle in our evaluation of individual patients.

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