

Disclosure please!

Jannie Louw taught us not to tell! He was an excellent teacher and an internationally recognised surgeon and was referring to the doctor's response to patients newly diagnosed with cancer. Why this advice? Because it was his experience that patients behaved irrationally on receiving serious bad news. This included becoming angry, tending to blame the doctor or others, and denying that there was anything wrong with them. He suggested that if there was no other way to cope one could perhaps take the spouse into one's confidence, but ensuring that they too kept the dark secret. Through the Hospice movement we have learned that such behaviour is a normal part of the grieving process following severe loss, including having to face one's vulnerability on receipt of personally catastrophic news. It has also clearly been demonstrated that the best way to deal with such situations is an honest disclosure to the patient. Telling the patient must of course be done kindly and with support to the patient and family through understanding and acceptance of the normal grieving process. This complete turnabout of how illnesses and responses to it are dealt with provides another example of how medical practice changes on the basis of better evidence, unlike other belief systems.

Disclosure of a patient's status enables rational discussions to occur about prognosis and treatment options and assists all to participate in making a properly informed decision. While accepting these truths for cancer, South African society has largely not come to grips with the same principles for HIV/AIDS.

Stigma and discrimination

The problems of HIV-related stigma, discrimination and human rights violations are addressed in an excellent publication by UNAIDS.¹ They note that visibility and openness about AIDS are prerequisites for the successful mobilisation of government, communities and individuals to respond to the epidemic. However the stigma associated with AIDS has silenced open discussion, both of its causes and of appropriate responses. By attributing blame to particular individuals and groups that are 'different', others can absolve themselves from acknowledging their own risk, confronting the problem and caring for those affected. Stigma has been described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. When stigma is acted upon, the result is discrimination. Confronting stigma and discrimination is a prerequisite for effective prevention and care. The negative effects of stigma and discrimination can be seen along each of the aspects of the continuum of prevention, care and treatment of HIV/AIDS.

South Africa has had its share of heroes. In the realm of public disclosure of their own HIV status these have included Supreme Court Judge Edwin Cameron, Zackie Achmat (head

of the Treatment Action Campaign – TAC), and Gugu Dlamini, who was killed by her KZN community because of disclosing her HIV-positive status. Political leaders such as Nelson Mandela and Gatsha Buthelezi have acknowledged that the death of near family has been the result of AIDS. But these remain the exception to the rule of denial.

Cameron's story

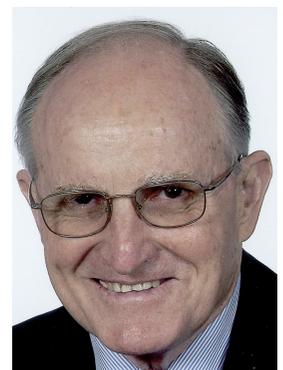
Edwin Cameron graphically describes his own personal journey from denial to full public disclosure of his positive HIV status (and also the fact that he is gay).² His health declined dramatically as a result of serious opportunistic infections before he was able to access effective antiretroviral therapy. The emotional turmoil of guilt and fear of discrimination was very real as he faced the possibility of early death. The effects of the way in which his diagnosis was conveyed to him via an unprepared telephone call are a stark reminder of the importance of providing counselling to recipients of such news. We are already accustomed to the fact that antiretroviral drugs are available and at an affordable cost. But Edwin's story of his own privileged access to such medication and the amazing influence of South African society in forcing the issues with our own health department and with international pharmaceutical companies is compelling reading.

What about the contentious matter of a prominent public figure expressing views seemingly at variance with those of the President's office and the Department of Health on HIV/AIDS, *inter alia* as reported in the *Mail and Guardian*? Edwin takes personal responsibility for what he said and for the public position he held when he said it. He also notes that his interventions of AIDS explored the limits of judicial participation.

Where to now?

People living with HIV and AIDS should be able to live openly and experience compassion and support within their communities. Their open example personalises the risk and experience to others, thereby aiding prevention, treatment and care efforts. We know enough to appreciate that disclosing the truth is the first step to dealing positively with difficult problems. Let's get on with disclosure please!

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1. UNAIDS Best Practice Collection: HIV-related stigma, discrimination and human rights violations. Report 14/4/2005.
2. Cameron E. *Witness to AIDS*. Cape Town: Tafelberg Publishers, 2005.