

COMMENTARY ON JUDGE CAMERON'S SPEECH

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In May 2006, Judge Edwin Cameron, probably the most high-profile South African living openly with HIV, delivered a lecture at the University of KwaZulu-Natal in honour of Professor Ronald Louw. Professor Louw, a lecturer in the Faculty of Law at the university, a member of the Treatment Action Campaign and a human rights activist, had died a few weeks earlier of an AIDS-related illness. Despite his access to information about HIV, and to adequate resources to manage his illness, Professor Louw had not tested for HIV, and by the time his HIV status was discovered he was too ill to benefit from treatment.

Judge Cameron, himself a well-known advocate for the human rights of people with HIV, suggests that the time has arrived to re-assess HIV testing procedures, in particular whether the current protocol, which includes access to both pre- and post-test counselling, informed consent and guaranteed confidentiality, is acting as a barrier to the scaling up of HIV testing, and contributing to further self-stigmatisation of people with HIV. While acknowledging the continued prevalence of external stigma, he expresses a profound and moving concern that the safeguards around testing are now reinforcing 'the inner fears and dread – the inner sense of self-contamination – of those who suspect that they may have HIV'. He controversially suggests that the exceptionalisation of HIV, including the strict requirements regarding testing, now constitutes a source of risk and harm to people with HIV.

Judge Cameron advocates routine testing. He suggests that where antiretroviral treatment is available and can be offered to the patient, where the patient is assured that he or she will not be discriminated against if they have HIV and where adequate safeguards exist to ensure confidentiality of the test and its outcome, HIV testing must take place unless the patient expressly refuses the test. He acknowledges that counselling is useful, but that it should only be provided if 'a health care facility is able to offer it without sacrificing the time and

The Tshwaranang Legal Advocacy Centre to end violence against women is an NGO that aims to make the legal system a vehicle of social change for women by influencing policy and legislation through advocacy, training and education, research and information dissemination.

energy of its health care personnel! That time, says Judge Cameron, 'is urgently required for diagnosis and treatment of HIV'.

Judge Cameron's lecture coincides with increasingly loud calls by public health authorities, including the World Health Organization (WHO), for a move away from the traditional voluntary counselling and testing (VCT) model. Options being debated range from routine offers of testing to all patients at all points of contact with the health system, to routine testing where patients must expressly state that they do not wish to be tested, the so-called 'opt-out model'. Some countries, e.g. Botswana, have already introduced a policy of routine testing. Public health officials arguing for this approach reiterate many of the arguments articulated by Judge Cameron and specifically point to the high costs of providing VCT in resource-poor settings. They argue that in high-prevalence countries there is great urgency to scale up HIV testing to facilitate access to antiretroviral treatment.

Human rights activists, however, continue to advocate for VCT, arguing that other models, where consent and counselling are not central to the process of testing, will violate basic human rights norms and expose unprepared and vulnerable individuals to stigma, discrimination and prejudice.¹ An international symposium on HIV testing and human rights in September 2005 concluded that 'Informed consent, counseling before and after a test, and confidentiality of test results are all grounded in human rights norms. Forms of HIV testing that significantly curtail these elements are not acceptable.'

There is currently a lack of empirical data confirming the effectiveness of any of these approaches, and there is clearly a need for research that will develop a detailed understanding of the benefits and disadvantages of different models of testing. Data regarding the experiences of people who are tested, and their responses to the process and the test result, must be gathered and are crucial to building an understanding of what the best model is to encourage testing and knowledge of HIV status. Attention should be paid to the specific needs of vulnerable groups, including women, gay men and sex workers, and their experiences of testing.

In the absence of such research, however, there is little to suggest that VCT does not work, and in my view it has much to recommend it, especially for women. I do not mean to suggest that VCT is not equally important for men, merely that

there is a specific context for women that must be carefully considered when assessing which models of HIV testing will be most effective.

Despite a plethora of laws and policies that provide for equality and non-discrimination, South African society continues to be characterised by high levels of inequality between men and women, and disturbingly high levels of violence against women. This context suggests that programmes intended to facilitate greater access to HIV testing and treatment for women, especially poor women who rely on the public health system, will not be successful unless they take these realities into account. In the context of sexual violence, research internationally and locally has affirmed the importance of access to adequate psycho-social care for survivors of gender-based violence, and activists and service providers continue to emphasise the importance of this access as part of the healing process for women. The lack of resources committed to providing this care has been a source of ongoing advocacy and lobbying. The value of counselling is starkly illustrated by research² conducted into adherence to post-exposure prophylaxis (PEP) after sexual assault, in Gauteng hospitals and clinics. This research reveals that PEP services are significantly undermined and weakened if they are not supported by access to counselling and properly integrated into other services for women. The research also shows that women themselves see counselling as necessary and important to their health and well-being.

The provision of counselling should therefore be seen as an essential part of a package of care for poor women who may suspect that they have HIV. For many women, this fear is exacerbated and reinforced by additional fears of violence,

abandonment and loss. Although there is also little empirical research regarding the true extent of HIV-related stigma and discrimination, there is sufficient anecdotal evidence to show that it continues to be a major problem that must be addressed. Pre-test counselling represents one of the very few opportunities for poor women to access any form of psycho-social care where they can discuss their fears and concerns regarding their health status and the consequences of a positive test result for themselves and their families, and where they are able to develop strategies to cope with HIV and its potential impact on their lives. Post-test counselling plays an equally important role – for those women who are negative, it is a chance to receive and discuss information that could save their lives; for those who are not, it is a safe space to begin the process of coming to terms with having a life-threatening illness.

For many poor women, VCT may also have an important symbolic value. Living in deeply sexist societies, for many it is the first opportunity where their rights to autonomy and agency are respected and encouraged.

So, rather than eliminating VCT, it should adequately resourced so that it is more widely accessible and effective – some research has suggested that the quality of counselling is weak. It should also be integrated more holistically into health services so that it can support and strengthen health services generally.

REFERENCES

1. Briefing paper, 'Outcomes of the Symposium on HIV Testing and Human Rights, 24-25 October 2005', Canadian HIV/AIDS Legal Network.
2. Vetten L 'Factors affecting adherence to post-exposure prophylaxis in the aftermath of sexual assault: Key findings from seven sites in Gauteng Province', 2004.

