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# A Human Rights Approach to HIV Testing: Voluntary, Mandatory or Routine?

Despite the demonstrated impact that knowledge of one's HIV status can have on the prevention and reduction of sexual HIV transmission<sup>1</sup>, many estimates suggest that worldwide over 90% of people currently living with HIV are unaware of their HIV status.<sup>2</sup>

Knowledge of one's HIV status can impact not only prevention, but can also be crucial for people to make informed choices about treatment, care and support services. Thus, HIV testing can play a vital role in the reduction and treatment of HIV. To facilitate access to this critical information, many governments have adopted HIV testing protocols. Currently, there are three primary types of HIV testing protocols existing: voluntary, mandatory, and routine testing.<sup>3</sup> While the benefits derived from HIV testing may be remarkable and significant, an unqualified endorsement of any type of HIV testing, as a means to reduce the prevalence of HIV, is incomplete.

Central to the HIV testing discourse are considerations of legal, constitutional, and human rights. In South Africa, everyone has the constitutionally guaranteed right to dignity (Constitution<sup>4</sup>, Section 10), the right to privacy (Constitution, Section 14), and the right to autonomy and bodily integrity (Constitution, Section 12). Section 12(2)(c) of the Bill of Rights, protects everyone against 'medical or scientific experiments without their informed consent'. Furthermore, Section 8(1) of the National

Health Act (No 61 of 2003) states that 'a person has the right to participate in any decision affecting his/her personal health and treatment'. Thus, with consideration of the aforementioned legally protected rights, when adopting a national HIV testing protocol, it is of paramount importance to select a model, which adheres to these rights. While each of the three models of HIV testing provides a number of advantages and disadvantages within a legal and human rights context, only voluntary HIV testing can be said to be grounded in an approach which adheres to the constitutionally guaranteed rights of South Africans.

## VOLUNTARY COUNSELLING AND TESTING

Voluntary Counselling and Testing, commonly referred to as VCT, is the standard HIV testing model used in South Africa, as well as in many other countries throughout the world. With VCT, individuals voluntarily elect to submit to HIV testing, to get to know their HIV status. Since VCT assumes pledge of confidentiality, counselling, and a voluntary choice – one which is theoretically free from all forms of coercion – many argue that VCT is anchored in a human rights approach and aligned with the constitutionally guaranteed rights in South Africa. By taking a rights-based approach, VCT arguably respects individual autonomy, dignity,



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# Editorial

*There is an important consensus that the right to health is not just about access to services, but to services of a well defined quality and a core element of that is that services should be designed as much as possible to minimise human rights abuse, including discrimination that may actually be associated with the intervention or the service. (...) ... ensuring access to HIV testing with counselling, informed consent and confidentiality is indeed well established as part of the human rights obligations of governments, [and] testing services should be designed to strive to minimise abuse and maximise benefits, including the link to treatment...* [Joanne Csete, Canadian HIV/AIDS Legal Network, August 2006]

The question of 'access to services', and specifically the access to HIV testing services, as well as the extent to which people are in the position to realise, participate in, and benefit from, available HIV testing services has, in the context of the global call for 'HIV testing scale-up', become the centre of debates. While the introduction of 'routine testing for HIV' has emerged as the proposed means to scale-up HIV testing, so have numerous concerns about human rights abuses imminent to this approach of 'opt-out routine testing for HIV'.

Notwithstanding the need to scale-up HIV testing, it is of utmost importance to ensure both human rights requirements and public health requirements, in identifying the mechanisms of how to respond to the need of scaling-up HIV testing. However, the current debate seems to be rather polarised in that the human rights requirements are seen to be contradictory to the public health requirements.

It is within this context of 'scaling-up HIV testing' and the emerging trend to change HIV testing models that this edition of the ALQ focuses on HIV testing. The various articles in this issue analyse different HIV testing models and approaches from a human rights perspective, and examine the extent to which the global call to scale up HIV testing, through the model of 'provider-initiated opt-out routine testing', creates an environment in which the fundamental human right to make an informed choice whether or not to test for HIV can be upheld, respected and protected. The implications of the move towards 'opt-out routine HIV testing' and its impact on human rights principles of informed consent, confidentiality and non-discrimination; concern about changing HIV testing strategies; arguments for and against voluntary, mandatory and routine HIV testing; human rights issues

emerging after the introduction of the 'opt-out routine HIV testing' programme in Botswana; as well as the theory of HIV testing as a preventative measure are some of the issues explored in this edition. This issue is also introducing findings from a study exploring perceptions about gender, HIV and AIDS and stigma in Khayeltsha, Western Cape; experiences of HIV testing policy and reality in Nigeria; 'making a point' about prisoners' access to ARVs; and providing comments on the criminalisation of HIV transmission, on HIV testing and rights of women living with HIV and AIDS, as well as on the need to scale up VCT.

In this edition, **Brandis Anderson** examines various HIV testing protocols as to the extent to which HIV testing models recognise and protect human rights. Exploring the numerous arguments of the proponents and opponents of voluntary, mandatory and routine HIV testing, she argues that of the HIV testing models available, voluntary counselling and testing is the one most firmly grounded in a human rights framework and, thus, the HIV testing model that should be promoted as an integral part of the response to the HIV pandemic.

The implications of the move towards provider-initiated opt-out HIV testing and away from voluntary counselling and testing are discussed by **Beri Hull**. Examining various realities of HIV testing, gendered imbalances and existing stigma and discrimination, she argues that since many people in many contexts are not equipped to 'opt-out', routine opt-out HIV testing is not a real choice for many people; and fails to take into account that people should get tested for HIV only as and when they are ready, prepared and willing to be tested for HIV.

Responding to the global call to scale-up of HIV testing, **Sofia Ruskin** raises concerns about some of the changes to HIV testing strategies. She explores issues of language, motivation, implementation and content of HIV testing strategies, and argues, that while there is a clear need to scale-up HIV testing and to move towards the routine offer of HIV testing, for HIV testing strategies to be effective, policies and practices need to be sound in both public health and human rights terms.

Some of the critical human rights issues that emerged from introducing provider-initiated, opt-out routine HIV testing in Botswana are introduced by **Christine Stegling**. Reflecting on the adopted policy of HIV testing based on an 'opt-out approach', which does not require the patient's expressed informed consent, and looking at the societal context in which HIV testing is taking place, she

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privacy, and bodily integrity, while providing an opportunity for an individual to make an informed choice regarding their HIV status. In addition to the VCT adherence to human rights, many studies indicate that VCT has been proven to be effective in reducing high-risk sexual behaviour and, subsequently, the spread of HIV. For instance, a study<sup>5</sup> of VCT programmes in Cape Town Townships demonstrated that VCT can result in behaviour change and can improve coping strategies of people living with HIV, by reducing risk behaviour.

Nonetheless, while arguments can be made that VCT protects the constitutional and human rights of the individual, questions have arisen challenging its effectiveness in reducing the prevalence of HIV, and the degree to which VCT protects collective rights. According to some statistics<sup>6</sup>, only one in five South Africans, who is aware of VCT, has been tested for HIV. Other statistics<sup>7</sup> suggest that only 850,000, of the more than 45 million South Africans, have been tested for HIV in the past four years, despite the availability of VCT testing centres and clinics.

Within this context, opponents of VCT assert that when a society has a low acceptance of VCT, but a high prevalence of the virus, the

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personal autonomy of one is valued at the expense of the human rights of many, by permitting people to engage in high-risk behaviours without knowledge of their HIV status, which can have tremendous public health consequences. Other arguments presented against VCT emphasise that the socio-economic reality in South Africa makes access to VCT neither voluntary nor informed. In addition, existing inequality further limits the choices of individuals seeking HIV testing. Individuals, particularly women, are often prevented from submitting to HIV testing by the fear of the social outcome of that decision. According to the Center for Women's Global Leadership (2006),

*...women who are, or who are perceived to be, infected with HIV may face violence and/or abandonment. Fear of violence associated with gender discrimination and the stigma that often comes with being HIV-positive can dissuade women from... getting testing for HIV.<sup>8</sup>*

Thus, while VCT may seemingly conform to human rights notions of voluntary and informed choice, it could be argued, that if society, or cultural factors, prevent individuals from exercising their voluntary choice, then perhaps a more proactive and aggressive HIV testing approach is necessary.

**MANDATORY OR COMPULSORY HIV TESTING**

Another testing model is mandatory or compulsory HIV testing. The ones in favour of mandatory testing generally present a utilitarian argument in support of their position. Under this utilitarian theory,

proponents of mandatory testing assert that it is permissible to abridge the rights or liberties of some individuals for the purposes of accomplishing the greater good for the larger society.<sup>9</sup> Since no rights are absolute, if rights-based methods prove ineffective in responding to a pandemic, such as the HIV crisis in South Africa, it is asserted that it is then necessary to adopt alternative approaches that are more effective, even if they constitute an infringement on some people's rights. Thus, in the context of the HIV pandemic in South Africa, supporters of compulsory HIV testing argue that in response to the current public health crisis, privacy and autonomy are outweighed by the countervailing duty for the preservation of life.

In addition to utilitarian justifications, proponents of mandatory HIV testing also present a number of pragmatic justifications. First, noting the level of infidelity and sexual exploitation in South Africa, proponents of mandatory HIV testing argue that to have the state bear responsibility for HIV testing would remove a burden from women, by forcing men to learn their HIV status, which could compel men to engage in safer sexual practices.<sup>10</sup> A survey conducted in South Africa<sup>11</sup> showed that men only account for 21% of clients receiving VCT, and that men, while more likely to engage in high-risk sexual behaviour, are reluctant to learn their HIV status, which places their sexual partners at increased risk of HIV transmission. Secondly, such an HIV testing framework would also allow sexually-active minors better access to learn their HIV status, since they could be tested for HIV without parental permission and/or notification. And finally, supporters of mandatory HIV testing argue that adopting this testing model would dramatically increase the number of people who know their HIV status, and thus, with greater number of people knowing their HIV status, the stigma associated with HIV would diminish.

Nonetheless, despite the arguments presented in favour of mandatory HIV testing, with few exceptions, mandatory HIV testing has been widely criticised as a grave infringement of human and legal rights, as well as an interference with privacy. However, in certain contexts, mandatory HIV testing has been seen as permissible. For instance, in Swaziland, all Umbutfo Swaziland Defence Force personnel have to submit to HIV testing,<sup>12</sup> and in South Africa, parliament is

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argues that there is a need to re-visit the routine opt-out HIV testing programmes in Botswana, since these programmes do not protect or respect the fundamental human right to make an informed choice.

Recognising the need to scale-up HIV testing, **Anand Grover** raises the question as to whether or not opt-out routine testing for HIV is the best option to achieve this. He analyses the opt-out routine HIV testing strategy as to its impact on principles of consent, pre-test counselling and the assurance of non-discrimination, and argues, that the strategy is flawed, since it fails to recognise and protect the individual's rights to pre-test counselling and informed HIV testing, and lacks the guarantee of confidentiality and non-discrimination.

**Emma Harvey** raises the question as to whether or not HIV testing can be seen as an effective prevention measure. Examining some of the evidence for and against the theory that voluntary counselling and testing is an effective HIV prevention measure, she argues that as long as stigma and discrimination poses a barrier to HIV testing, the potential that HIV testing contributes to behavioural change and thus, HIV prevention, remains rather limited and nothing more than a theory.

Findings from a research study exploring various factors that contribute to the stigmatisation of women living with HIV and AIDS are introduced by **Tshipinare Marumo**. He argues that women, due to their social and economic status, are not only more at risk of HIV infection, but also much blamed for their HIV infection and thus, women living with HIV and AIDS experience HIV and AIDS related stigma and discrimination very different.

The realities of HIV testing in Nigeria are introduced by **Busari Olusegun**. He discusses the conditions of the Nigerian healthcare sector and argues that as long as there is a general lack of knowledge on patients' rights and a failure to provide workplace safety for people working in the health sector, voluntary counselling and testing will only exist in the realm of policy, since the reality is one of being between patients' rights and doctors' safety.

Looking at the recent Court judgement against Durban Westville Correctional Centre, **Lukas Muntingh** and **Christopher Mbazira** are '*making a point*' about prisoners' right of access to anti-retroviral treatment. The article examines the facts, arguments and judgement in the case and argues that the case reinforces the jurisprudence of socio-economic rights in South Africa, in that it is a pronounced expression of prisoners' right of access to healthcare and the duty of the state to provide such access.

While there seems to be a common understanding of

the need to scale up HIV testing and the importance for people to be aware of their HIV status, there also seems to be an equally strong concern about the methods adopted to achieve a scale up in HIV testing and the seemingly inevitable human rights violations, if '*opt-out routine testing*' is to become the newly adopted approach to HIV testing. The underlying question raised seems to be whether or not the need to scale up HIV testing does, and can, in any way, justify sacrificing fundamental human rights principles of informed consent, security of a person, confidentiality and non-discrimination. The recurring answer seems to be that human rights principles are to be the foundation of any HIV testing model, especially considering the societal context in which HIV testing takes place – one which is characterised by gendered inequalities, imbalances and injustices, as well as prevailing stigma, discrimination and the violation of rights based on, and in the context of, HIV and AIDS – a societal context, in which the '*right to opt-out*' seems to be a privilege for a few.

However, there also seems to be the need to acknowledge that voluntary counselling and testing, as the promoted HIV testing model within a human rights framework, has not achieved its goal – considering statistics indicating that more than 80% of people living with HIV are unaware of their HIV status – with a number of reasons recurrently provided for the low up-take in HIV testing services, including stigma and discrimination, lack of access to testing services and lack of awareness. Thus, while there is a strong concern about the inevitable human rights violations in the context of '*opt-out routine testing for HIV*', there is also the concern about existing human rights violations, which seem to be part of, and a barrier to, the access to voluntary counselling and testing for HIV.

If we are to agree that it is important to be knowledgeable of one's HIV status so as to access HIV treatment, care and support services, then we need to examine the availability and quality of these services, to be in the position to evidence the created causality. This would also include examining the extent to which available resources are in the position to provide for the '*scaled-up*' need in HIV testing services, as well as treatment, care and support services.

If we are further to agree that there is benefit to scale-up HIV testing, we need to ask ourselves who is to benefit – the individual, who may not have been prepared to test for HIV, or government who need to have accurate statistics to prepare an adequate response to the HIV and AIDS pandemics. Similarly, we may have to analyse the factors determining the '*need*' for scaling-up HIV testing – is it the many people who want to be aware of their HIV

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currently debating legislation, which would provide for compulsory HIV testing of alleged sexual offenders at the request of the victim. Nevertheless, mandatory HIV testing, in a universal form, on public health grounds, remains overwhelmingly opposed by nearly all actors in the HIV testing discourse.

In contrast to the utilitarian theory, presented in favour of compulsory HIV testing, the primary theory presented against such testing is deontological. Thus, opponents of mandatory HIV testing assert that human beings are afforded certain inalienable rights, which should not be taken away for any reason.<sup>13</sup> Mandatory HIV testing is a violation of the constitutionally guaranteed rights in South Africa, as well as a violation of universally accepted human rights codified in international agreements, including the International Covenant on Civil and Political Rights (ICCPR), which South Africa has ratified. The ICCPR states that *'no one shall be subjected to arbitrary or unlawful interference with his privacy'* and such a right to privacy would imply obligatory informed consent for HIV testing, which is inconsistent with mandatory HIV testing.

In addition to the rights-based argument presented against mandatory HIV testing, opponents also assert that such testing is a misallocation of limited financial resources that could perhaps better be spent on treatment or support, especially when a single HIV test has limited validity. Finally, opponents of compulsory HIV testing argue that this HIV testing model is largely-ineffective, since if one forces someone into HIV testing, one has not persuaded the person of the benefits of HIV testing, and therefore, one would likely have to also coerce the person into treatment and behaviour change.<sup>14</sup>

## ROUTINE HIV TESTING

The third testing protocol, which is gaining greater support in South Africa after Botswana introduced the approach in 2004, is routine testing. Botswana became the first African nation to adopt the approach after realising that a western HIV testing approach was not aggressive enough in countries where the prevalence of HIV is so high.

There are two primary forms of routine HIV testing; opt-in and opt-out. With *'opt-in'* HIV testing, anyone who enters a healthcare setting will be informed of the availability of an HIV test, but will only be given the test, if specifically requested. With *'opt-out'* HIV testing, it is presumed that anyone who enters a healthcare setting will be tested for HIV, unless the person refuses to consent to the HIV test. The effects of utilising the routine opt-out model of HIV testing in Botswana have been remarkable, with a 19% increase in HIV testing from 2004 to 2005.<sup>15</sup>

Proponents of routine testing argue that instituting this model of HIV testing, and thus, treating HIV like other diseases, would reduce the stigma associated with the virus. This assertion is based on a critical review of the historical reaction to the HI virus, which led to a form of *'HIV exceptionalism'*. In the early years of the virus, HIV was treated differently than other diseases, marked by a strong emphasis on informed consent and voluntary choice for testing, largely because of the few available treatment options, as well as the association of HIV with sexual behaviour and drug use, which led to a high degree of stigma and discrimination toward people infected with HIV.<sup>16</sup> Unlike other transmittable diseases, such as syphilis and hepatitis B, for which consent for testing is implied in the healthcare settings, testing for HIV has been avoided, which has, as could be argued, worked to increase the stigma surrounding the disease. Thus, supporters of routine HIV

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testing argue that the key to reduction of stigma associated with HIV is to begin to routine test for HIV in healthcare settings in a similar manner as with other diseases. Proponents of routine HIV testing also argue that routine testing could enable doctors to diagnose HIV at earlier stages, increasing the chances of treating the infected person. Finally, supporters of routine testing for HIV claim that since an individual's HIV status can continually change, especially if people continue to engage in high-risk behaviour, one single HIV test has only limited validity. With routine HIV testing, as individuals continue to engage in behaviours placing people at risk for contracting HIV, proponents argue that it would be beneficial for such individuals to have access to routine HIV testing, so as to continually monitor their HIV status.<sup>17</sup>

Despite the benefits of routine HIV testing, opponents claim that routine opt-out testing does not provide an easy way for a patient to decline an HIV test. A study of first-time antenatal clinic attendees in a South African hospital<sup>18</sup> showed the degree to which informed consent in medical settings is not truly voluntary, but instead can include subtle elements of coercion. In this study, participants were informed that their participation was voluntary, yet, 88% of the women stated they felt compelled to participate, with the majority expressing fear that they were not allowed to quit, and some even stating that they believed they would face negative consequences, if they did not

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status and demand 'scaled-up' HIV testing services, or is it the many policies who demand HIV testing, since people 'ought to be/should be' aware of their HIV status?

And if we are to find the answers to these questions within the human rights framework, then it is the fundamental human rights principles of a person's informed consent – provided free of fear of harm, free of coercion and imposition, free of 'moral obligations' – that is to form the basis for these answers.

There is also the argument of 'the right to opt-out'. This argument is often used by proponents of the 'routine HIV testing' model, to not only justify the very same, but also to justify that 'routine testing' for HIV is not as an abuse of human rights, since people are not tested compulsory, but instead given the 'choice to opt-out'. However, if we were to agree that the 'right to opt-out' does, to an extent, adheres to the human rights principle of informed consent, then we have to carefully examine the extent to which people are in the position to realise the 'right to opt-out'.

Recognising the different and often unequal conditions and contexts in which people access healthcare services, and thus, provider-initiated opt-out HIV testing services, demands acknowledging that the very same different and often unequal conditions and contexts are the factors determining the extent to which people are in the position to access, realise and benefit from the 'right to opt-out'. Thus, the question does not seem to be whether or not there is a 'right to opt-out', but whether or not people are 'equipped' to claim and enjoy this right; and whether or not people are equally 'equipped' to claim and enjoy this right. And, as with any right, reality is not defined by the right itself, but instead by the societal context in which the right is to be accessed and realised. And so, as with any right, the 'right to opt-out' is a right for the privileged few, who are 'informed, equipped and empowered to opt-out'.

But even if we are to live in a society in which everyone is equally informed, equipped and empowered to 'opt-out', we still may have to ask the question as to why people choose to 'opt-out' from HIV testing. Is it because people choose to 'opt-out' from the benefits of HIV testing; or is it because people perceive themselves at low risk of HIV infection; or is it because people choose to 'opt-out' for fear of an HIV positive test result and the fear of subsequent stigma, discrimination and abuse? While the reasons for a person to 'choose to opt-out' may be many and differ in various conditions and contexts, the underlying question as to whether or not the societal context of HIV testing characterises, what would be called, an 'enabling environment' to freely claim and

enjoy the 'the right to choose to opt-out' remains. And in the societal context of gendered inequalities and prevailing discriminatory attitudes, beliefs and practices based on one's sex, gender, sexual orientation and/or HIV status, the answer to this question seems to be an easy one – no!

Thus, as long as the societal context in which HIV testing takes place is filled with human rights violations based on, and in the context of, HIV and AIDS, the question is not one of the adequate HIV testing model, but one of creating an enabling environment for HIV testing. And this enabling environment cannot be based on the 'right to opt-out' of HIV testing, irrespective of whether or not stigma, discrimination and the violation of rights prevail, but based on the 'right to opt-in', the 'right to informed consent' to HIV testing, because people are 'willing, ready and prepared' to test for HIV, 'willing, ready and prepared' to test positive for HIV.

Until reality provides for the 'freedom to opt-in' to HIV testing, we will have many more heated debates about voluntary counselling and testing, as the human rights approach to HIV testing, versus provider-initiated opt-out routine HIV testing, as the imminent human rights abuse; about the 'right to informed consent' versus 'the right to opt-out'. Unfortunately, in the meantime, there will be many more people 'choosing' to 'opt-out' of the benefits of HIV testing – and, in many cases, even against better knowledge – due to pervasive stigma and discrimination, due to our seemingly reluctance and failure to engage in equally heated debates about the means of addressing stigma and discrimination, which after all is the recognised barrier to HIV testing.

A global policy call to scale-up HIV testing does not and cannot carry the potential to address, nor respond to, the reality of prevailing stigma and discrimination based on, and in the context of, HIV and AIDS, since policy cannot transform the 'right to know one's HIV status' to the 'freedom to know one's HIV status'. However, challenging and transforming the societal context in which HIV testing takes place does indeed carry the potential to scale-up HIV testing, carries the potential to respond to the need of scaling-up HIV testing within a human rights framework – in that HIV testing services are designed 'to minimise abuse and maximise benefits', and 'the right to opt-out' becomes 'the freedom to opt-in'...

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participate in the study. Even outside the cited study setting, anecdotal evidence suggests that presently many pregnant women are routinely coerced into HIV testing, without any information provided by the healthcare worker of the right to 'opt-out' of such testing.

Thus, as demonstrated by these situations, routine HIV testing is not anchored in a human rights approach, since it infringes on the voluntary choice by coercion and/or lack of informed consent. In addition to the coercive elements, routine HIV testing could also have an impact on the valued doctor-patient relationship, if patients feel that they are pressured and/or coerced into HIV testing, and thus, patients may feel discouraged from seeking treatment for other illnesses or from seeking medical treatment altogether. The consequences of this breakdown in relationship could foster tremendous medical implications.

Finally, opponents of routine HIV testing argue that, considering the current resource and time constraints in the medical setting, routine testing would likely neglect the most important aspect of the HIV testing consultation – counselling. Considering the rates of clinical depression and suicide amongst people who test positive for HIV, one of the most important elements of the HIV test is the pre- and post-test counselling. Such counselling is essential to provide advice on both safer lifestyle choices and the implications of an HIV test result. In a public healthcare setting, where a doctor in South Africa spends on

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average only twelve minutes with a patient, there is little or no time or resources readily available to provide the requisite pre and post-test counselling in a manner that adequately conveys the necessary information to the patient.<sup>19</sup>

### SUMMARY

Overall, HIV testing can serve a critical role in reducing the prevalence of HIV in South Africa and worldwide. While there are three primary HIV testing models, considering that everyone in South Africa has a constitutionally and legally protected right to privacy, dignity, autonomy and bodily integrity, VCT, despite its flaws, appears to be the only option that is truly aligned with these rights, and protective of an individual's right to voluntary choice free of coercion. Even moving beyond rights, VCT, if scaled up, and perhaps made more accessible, is likely to be the most effective option, since HIV testing alone does not reduce the prevalence of HIV, but rather the lifestyle changes and treatment decisions that follow, impact the prevalence of the virus. Thus, individuals who have voluntarily elected to test for HIV are, arguably, more likely to derive benefits from the HIV test and, therefore, more likely to adopt the necessary lifestyle changes and treatment options.

While few would dispute that the HIV and AIDS pandemics are a

national emergency in South Africa, requiring a concerted and extensive response, it is important to not abridge the most fundamental rights and liberties in crafting such a response. Of the HIV testing models available, VCT is the most firmly grounded in a human rights approach and thus, VCT should be promoted as part of South Africa's response to the HIV pandemic.

### FOOTNOTES:

1. A 2005 meta-analysis demonstrated the knowledge of HIV status can reduce risk of sexual HIV transmission by 68%. See also Marks, G. et al. 2005. 'Meta-Analysis of High-Risk Sexual Behavior in Persons Aware and Unaware They are Infected With HIV in the United States: Implications for HIV Prevention Programs'. In: *AIDS Journal of Acquired Immune Deficiency Syndromes*. Vol. 39(4).
2. Rabinowitz, R. 2005. 'Mandatory Premarital HIV Testing Could Reduce New Infections'. 16 March 2005.
3. A fourth testing protocol, 'diagnostic testing', exists. However, it will not be discussed in this paper. Diagnostic testing is testing when a person displays symptoms consistent with HIV or AIDS-related diseases in order to assist in clinical diagnosis and management.
4. The Constitution of South Africa, Act 108 of 1996.
5. Thiede, M. 2004. 'South Africa: Who Goes to the Public Sector for HIV/AIDS Counseling and Testing'. Oct. 2004.
6. Kalichman, S. & Simbayi, L. 2003. 'HIV Testing Attitudes, AIDS Stigma, and Voluntary HIV Counselling and Testing in a Black Township in Cape Town, South Africa'. In: *Sexually Transmitted Infections*. No. 79:422.
7. Health Systems Trust. 2005. 'Government to Consider Routine Testing'. 08 November 2005. (<http://www.hst.org.za/news/20040908>)
8. Center for Women's Global Leadership. 2006. *Strengthening Resistance: Confronting Violence Against Women and HIV/AIDS*. August 2006, forthcoming.
9. Markkula Center for Applied Ethics. 1990. 'AIDS, Privacy & the Community: The Ethics of Mandatory Testing and Disclosure'. Summer 1990.
10. IRIN. 2006. 'South Africa: The HIV Testing Debate: Voluntary or Opt-Out?'. 16 May 2006.
11. IRIN. 2005. 'South Africa: Men Falling Through the Cracks'. 25 July 2005.
12. IRIN. 2004. 'Swaziland: Army to Introduce Compulsory HIV Testing'. 3 February 2004.
13. Markkula Center for Applied Ethics. 1990. 'AIDS, Privacy & the Community: The Ethics of Mandatory Testing and Disclosure'. Summer 1990.
14. Jack, A. 2006. 'Clinton Stirs Debate with Backing for Mandatory Testing'. 25 April 2006.
15. It is important to note that the effectiveness of Botswana's programme may be attributed to the fact that its HIV testing model is backed by national free access to antiretroviral treatment. See also LaFraniere, S. 2004. 'Mandatory Tests Bolster Botswana's War on AIDS'. 14 June 2004.
16. De Cock, K. 2006. 'Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century'.
17. Oberman, M. 1996. *Genetics and the Law*. University of Chicago Law School.
18. Karim, Q. A. 1998. 'Informed Consent for HIV Testing in a South African Hospital: Is it Truly Informed and Truly Voluntary?'. April 1998.
19. Banderker, N. & Van Belle, J-P. (n.d.) 'Mobile Technology Adoption by Doctors in Public Healthcare in the Western Cape, South Africa'. Cape Town: University of Cape Town.

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# Should we be wary of ‘opt-out’ testing?

## Routine HIV Testing and Context<sup>1</sup>

I write as someone who has gone through the fear, apprehension, sadness and eventual acceptance of receiving a positive HIV diagnosis. Before I made the decision to take an anonymous HIV test, I had garnered a strong base of personal support. But even then, I would not have tested for HIV when I did, if it had not been anonymous. I also have had an optimal resolution in dealing with internal stigma and minimal direct experience with external stigma. Testing HIV positive and the journey from denial to acceptance of my HIV status has been empowering and influential in making me who I am as a person today. I encourage and support everyone, who has engaged in risky behaviour, to get tested – when one is ready, willing and able.

### Thinking about HIV testing

It is critically important for anyone to be prepared to receive a confidential, positive HIV diagnosis. That preparation includes access to care, treatment and support. It is also important that one makes a cautious assessment as to how safe one will be from stigma, discrimination and/or violence, should one’s status be intentionally or unintentionally revealed. And it is important to take into account one’s ability to cope with depression and/or self-destructive behaviour as a result of being tested HIV positive.

### Why the debate

These issues are important today, because of the push by some governments and public health authorities, including WHO and UNAIDS, for routine provider-initiated (PIT) opt-out HIV testing, in place of what has been known traditionally as voluntary counselling and testing (VCT).

### What is the difference between these two different approaches to HIV testing?

In the call for scaling up HIV testing, it is being suggested that informed consent and counselling are acting as barriers to testing and should be diminished or removed. The solution, supporters claim, lies in provider-initiated opt-out HIV testing of virtually every person going for clinical care. In these settings, everyone would be offered an HIV test, with or without informed consent or pre-test counselling. If one does not want the HIV test, one must explicitly state that. If one doesn’t, one will be tested for HIV.

The difference between opt-out testing and traditional voluntary counselling and testing is that with VCT, a person in a clinical setting would either request an HIV test or, if offered one, would have to explicitly agree to take the test (opt-in). If a person says nothing, the HIV test would not be given. In the opt-out model, if a person says nothing, the person will get tested for HIV.

Supporters of opt-out HIV testing claim that:

- VCT, as we know it, has not worked in reaching people who are untested and HIV positive
- AIDS, with regards to testing, has served as a barrier to testing uptake exceptionalism (informed consent and pre/post test counselling are considered exceptionalism, when it comes to disease testing)
- AIDS exceptionalism, with regards to testing, is fuelling stigma
- It is untested HIV positive people who are spreading the virus
- If more people know their status, there would be less transmission of HIV
- Provider-initiated, opt-out testing will ‘normalise HIV testing’
- HIV testing is the gateway to care, treatment, support and prevention services and the lack of testing uptake is impeding service access and delivery

Although I agree that HIV testing scale-ups should include the offer of an HIV test, I also believe strongly that informed consent and counselling should remain intact, and be enhanced, to make sure that these include the information needed to prepare a person for a positive HIV diagnosis. Preparation for a positive HIV diagnosis should include access to care, treatment, support and information. It must also take into account the existing political environments and laws that protect (or not!) people living with HIV from stigma and discrimination.



I do not agree with the concept of opt-out testing. There will be many people in many contexts and circumstances, who will not be equipped to 'opt out'. What is being referred to as voluntary provider-initiated, opt-out, testing, will in fact be involuntary, provider-initiated, opt-out testing.

### **Why opt-out testing is not a real choice for many**

Power, gender, race and class inequities make opt-out HIV testing difficult, or even impossible, for many women and men. At the 2006 International AIDS Conference in Toronto, we heard over and over again how women had to be empowered in order to stop the spread of AIDS and all the reasons why so many women have only glimpsed what it means to have the power, confidence, gender or economic equality they need to make informed, meaningful choices. Why would these barriers suddenly be meaningless in the context of HIV testing? Language and comprehension challenges will also mean that opting-out and the lack of informed consent will in effect mean mandatory testing. What will happen to people when they test positive for HIV, and were not clear that they were being tested in the first place, or had little information on what the test would mean?

### **What about access to care, treatment and support?**

For all people already tested HIV positive globally, approximately 20% have access to ARV treatment. When opt-out HIV testing is implemented and more HIV cases are discovered, the percentage of people receiving ARV treatment will drop even further. Coercing people to be tested for HIV, where treatment, care and support are unavailable, is unethical. The repercussions for others who discover their HIV status and lose healthcare access are also unethical. For instance, in the United States, people who have access to medical care through private, expensive health insurance schemes, will lose their eligibility for healthcare coverage once they test HIV positive.

Another problem with opt-out testing, if a person is unprepared, is the risk of stigma, discrimination and violence. Although HIV testing is a gateway to services, unfortunately, HIV testing is also a gateway to stigma and discrimination. For example, women are often blamed for bringing the virus into their home or community. This blaming of women is facilitated, since women are often the first in families to be diagnosed, because of their engagement with different health services.

**...it is ... important that one makes a cautious assessment as to how safe one will be from stigma, discrimination and/or violence, should one's status be ... revealed...**

**...coercing people to be tested for HIV, where treatment, care and support are unavailable, is unethical...**

Women engage more with healthcare, through pregnancy and childbirth or through their care of other family members, while men are more likely to avoid healthcare. As a result, women are often subjected to blame, abandonment, discrimination and violence. A woman may choose not to be tested for HIV, because she is, on some level, aware of the potential abuse and violation – for her, deciding not to be tested, is a survival mechanism.

Stigma and discrimination is not only a family problem, as many HIV positive tested women report that much of the stigma and discrimination comes from healthcare providers directly. Thus, the question has to be raised as to how such circumstances will affect a person's ability or decision to opt-out of taking an HIV test?

Less talked about and rarely brought up are the realities of self-violence<sup>2</sup> and depression, which is a problem even for people who voluntarily seek out HIV testing. And, how much worse will this be for people who are not empowered to opt-out, or are confused about being tested for HIV in the first place?

### **What does 'normalisation' mean?**

I agree that there should be nothing unusual in an HIV test being given or taken. However, calling for the normalisation of HIV testing seems out of place and inappropriate, without the call for the normalisation of HIV prevention provision and care services first. In the USA, for example, the government talks about the 'normalisation' of HIV testing, but does not support harm reduction, needle exchange or comprehensive sex education or prevention

**Should we be wary of 'opt-out' testing?**

for youth. Even if HIV testing is to become 'normal', it will never be 'normal' to receive a positive HIV diagnosis.

What routine testing advocates do not address, is where the resources needed to scale-up HIV testing will come from in a world where the majority of people already tested HIV positive do not have access to care, treatment and/or support.

We know that as treatment becomes available, more people utilise VCT. Why not push for a scale-up of HIV treatment first and see if the increased demand for HIV testing, and the resulting HIV cases found, can keep up with the demand for treatment. Of course, anyone who wants HIV testing and treatment should be accommodated.

In a speech by South African Judge Edwin Cameron, inspired by the AIDS-related death of Ronald Louw, an AIDS activist, due to his own fear and internal stigma, and the refusal to be tested, despite extensive knowledge about HIV, Judge Cameron came out in support of routine testing. He also described the example of his gardener, who refused to be tested for HIV and has now died, even though, he would have been able to access treatment by virtue of being Cameron's employee. Cameron's examples, which were meant to bolster his support of routine testing, angered me, since he did not adequately address the reality of people who do not have access to treatment. His position is, arguably, based on the experiences of privileged males and people associated with them, compared to the situation of most people who live in poverty and do not have access to basic healthcare, let alone ARV treatment, is, in my opinion, short-sighted and unjust. I would also argue that the fact that Ronald did not get tested for HIV, to his own demise, because of internalised stigma, is testament to the fact that stigma is still a huge problem and that people must be prepared and willing to be tested for HIV – something that opt-out testing policies discount.

There are also the assertions that it is untested people who are spreading the HI virus and that as more people know their status, more will change their behaviour and

transmission rates will go down. These assertions are largely based on what has been learned from people who sought out HIV testing and made a conscious, informed decision to be tested for HIV via opt-in, VCT programmes. It is likely that people, coerced or unprepared to be tested HIV in an opt-out model, will not be as likely to change behaviour and will hold on to denial and internal stigma to the detriment of themselves and others. I have heard many such stories.

It is disturbing to me that the roll-out of routine HIV testing is being pushed by the United Nations, and in the USA, despite community concerns and without community consultation. It also surprises me that the United Nations is supporting opt-out HIV testing, considering its record of promulgating human rights, including the human rights of people living with HIV. It will be up to the local, national and global communities to monitor and report the impact and consequences of the policies and demand that people, who promoted them, do the same.

In conclusion, I want to state again how important it is for people to be aware of their HIV status – when they are ready, willing and able.

**...it is likely that people, coerced or unprepared to be tested HIV ... will not be as likely to change behaviour and will hold on to denial and internal stigma to the detriment of themselves and others...**

It is important in the response to the pandemics that at-risk communities and people be prepared to test HIV positive, which includes the access to care, treatment and support, and an environment that supports protection from stigma and discrimination. People living with HIV have a powerful role to play in making a way in this world for others, by offering support and self-acceptance in living with HIV.

And finally, I would like to dedicate this article to all the people who will suffer and/or die from stigma and discrimination after being diagnosed with HIV, and to all the women and men, infected with HIV, who will avoid healthcare, because they were afraid of being tested.

**FOOTNOTES:**

1. A shortened version of this article will be published in ICW News 35 and is available on the ICW website ([www.icw.org](http://www.icw.org)).
2. Forms of self-abuse include drug and alcohol use, sexual acting out, other addictive behaviors, unwillingness to seek necessary health care, staying in abusive relationships, and suicide.

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# Its time to deliver right!

## HIV Testing in the Era of Treatment Scale Up: Concerns and Considerations

At this point in time, one can generally assume that there is consensus that the HIV epidemics need to be addressed with maximum efficiency and urgency, as well as with sufficient attention to the well-being and security of concerned individuals and populations.

In terms of HIV testing specifically, this means from both public health and human rights perspectives that in addition to the numbers of people being tested, attention is needed in every instance as to why HIV testing is being carried out, how it is being carried out, whether or not, in the ways it is carried out, people are given the information they need to understand the implications of their results, and if they are infected, whether or not they can access the treatment and services that should be available to them.

The fact that treatment is finally starting to become more readily available implicitly means that HIV testing has to be scaled up, since the assumption is that people need to know their status in order to access treatment – if it is available. From a rights perspective, one can see there is an obligation to ensure that if HIV testing is performed, access to care, treatment and support need be not only a theory, but a duly implemented practice. Nonetheless, whether or not treatment is available, HIV testing is increasingly capturing the world's attention, and unfortunately many of the new efforts to scale up testing are being framed so that they appear to be pitting public health goals against human rights norms. The debate about correct approaches to HIV testing needs to be re-centred onto something that moves strategies forward towards sound public health and human rights practice, and away from a framing of public health and human rights as diverging or even antagonistic concepts.

With this in mind, there are four points of immediate concern, which I would suggest must be considered as HIV testing strategies are being revised and reconsidered.

The first issue concerns the need to pay far more attention to the implications of language and the use of acronyms. This is not only about semantics, but has critical implications for the development and implementation of policies and programmes. While the last year has seen the wholehearted adoption of the language of '*routine testing*', it is vague language, which has generated much confusion. Use of the language of '*routine testing*' does not clarify if the HIV testing is routinely offered or routinely imposed, and thus will require vigilance in each case where the term is used to determine exactly what is meant.

Another language issue concerns the move away from VCT, as the acronym of choice, when discussing HIV testing policies. There are significant differences between a VCT approach and a TC approach. This change in acronym may seem subtle, but it opens up a range of questions of how HIV testing strategies are, and ought to be, done. This is not to say that VCT, as traditionally understood to mean people

voluntarily coming forward out of nowhere to seek HIV testing, is the only way, and that a move towards a routine offer of HIV testing in health facilities, resulting in people voluntarily choosing to be tested, is not a useful and appropriate step forward. However, I find it incomprehensible that if HIV testing is done within a health facility, and offered by a provider, informed consent is no longer thought to play the central role it has traditionally in medical practice. As my colleague Daniel Tarantola says this is generally how one distinguishes human health practice from veterinary practice.

The second point to keep in mind in each case is the question of what is motivating the HIV testing strategy, as well as its implementation. Even a testing strategy which appears on its surface to be the same in different countries, will play out very differently depending on its motivation. A strategy will be implemented in a particular way, and with more attention to numbers than quality, if its motivation is primarily to report sufficient numbers of people being tested to government, and external donors, to show that programme goals are being met. In contrast, a testing strategy with a primary focus on ensuring people know, not only their HIV status, but its implications, including, if necessary, approaches to changing behaviours, may result in fewer absolute numbers of people being tested, but quite likely in a group of individuals and their families that feel engaged and fully connected to the health services over time.

A third issue which requires some thought, is how those concerned with changes in HIV testing strategies, as well as the media, use the names of the geographical locations where HIV testing policies are changing

## ...care is needed to ensure the rush to scale up HIV testing does not end up serving as a justification to mandatorily test populations whose actions fall outside the law...

drastically as a shorthand to make their points, but with little discussion as to the content of the policies that exist within these places. Beyond the fact that these changes have taken place with little or no say on the part of people subjected to HIV testing, of concern is that in the general and professional media, as well as at the Toronto Conference, San Francisco, Lesotho and Botswana are all specifically cited, and at times erroneously cited, as examples of routine HIV testing policies being put into place, even as little to nothing is said about their content nor the actual differences between them. Policy directives that provide for the routine offer of HIV testing with informed consent is often represented as systematic HIV testing with an opt-out possibility (more or less defined). This is not to defend or attack any of these policies, but simply to say that when these policies are discussed there must be far more clarity about what they actually say. There is a danger in simply citing geography to make points about HIV testing strategies. Efforts must be made to state explicitly in each case a range of issues including – how long and what the content is of the pre-test counselling offered; the actual process and approach taken to ensuring consent; the form that the ‘encouragement’ to be tested takes; whether or not treatment is available and, if so, if it is easily accessible over a sustained period of time.

The fourth and final point relates to identifying and addressing the gaps between policy and what actually occurs in practice. As an example, one need only consider the differences in how a routine HIV testing policy with generalised language, that pays little attention to gender differentials and vulnerable populations in how its written, will play out in two different scenarios. In one case, an employed middle class man comes voluntarily for another health issue to a provider’s office where the test is offered and explained including the long-term benefits of treatment – and one would guess the opportunity for rationale decision making offered. Time is given for post-test counselling and the provision of results. In contrast, consider the same policy, as it might play out for women in the context of pregnancy and childbirth, in particular around delivery. Significant issues may arise in this context around assuring consent, the ways in which counselling (pre and post) will be provided, how and when the woman will be informed of a positive test result, how confidentiality of that test result will be protected, and what links to services and treatment will exist for both the woman and the child, not only when she gives birth, but over time, in particular once the woman can no longer access whatever treatment there is through antenatal services.

As a related point, care is needed to ensure the rush to scale up HIV testing does not end up serving as a justification to mandatorily test populations whose actions fall outside the law, like injecting drug users or sex workers. This is an issue not only in health services, but there is a danger that these policies will change practices within institutions, such as immigration offices, police stations and prisons, with little attention to the long-term impact.

In conclusion, attention is needed to make sure that both in their design and in their implementation, as HIV testing strategies change, programmes ensure that decisions, about what sorts of HIV testing policies are in place, are made with full attention to community concerns and with the communities themselves. We also need to be sure that evidence is collected, as to the implications and effects of these policies and the practices they generate, beyond simply the numbers of people tested, in ways that are systematic and comparable. We need to be careful that those responsible for implementing and evaluating these policies pay enough attention not only to the hoped for outcomes of these strategies, such as decreases in stigma, ‘*normalisation of HIV*’, and strengthening of health services, but also the adverse outcomes that may arise, such as the increased stigma a person may experience if their HIV test results become known, the violence that may occur against the person and their family members, and the

## ...its time to deliver... sure... but its time to deliver right!...

burdens that may be placed on already strained health services that may not yet be equipped to handle the increased need and demand.

The need to scale up HIV testing is clear and strategies must move towards the routine offer of HIV testing. In the history of AIDS, we have been through many issues that are divisive. There is little doubt that these different approaches to HIV testing are well intended, even when they are misguided. We need to ensure policies and practices are sound in both public health and human rights terms – in order to be effective.

Its time to deliver...sure...but its time to deliver right!

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# Testing to what end?

## HIV testing in the era of increased treatment access: A perspective from Botswana<sup>1</sup>

The following comments seek to give a brief insight into some of the critical issues that have emerged out of the Government of Botswana introducing 'provider-initiated/opt-out routine testing'.

Testing for HIV is a starting point for any intervention, may it be prevention, care or support, including psycho-social support, and access to anti-retroviral therapy. While all of us might agree that it is crucial that as many people as possible have access to HIV testing, and actually make use of HIV testing facilities, only a few of us seem to agree on the question as to how the HIV test should be initiated, and what processes of HIV testing should be followed.

Unfortunately, this disagreement has been discussed in a rather polarised way; where human rights activists are placed on the one side and public health practitioners on the other. And this polarisation seems to say that public health does not have to be understood within the context of human rights, whereas the right to health, the right to information and the right to privacy are all interlinked with issues of public health, and, thus, ultimately contribute to well-informed citizens, making informed choices about their lives, looking after their health and, therefore, contributing to the general well-being of communities.

As human rights activists in Botswana, we find it highly regrettable that we are portrayed as obstacles to public health, and as people who have made HIV an exceptional disease. In actual fact, while we still believe that HIV is not like any other disease, many of the principles that we are arguing for, such as the right to informed consent, the right to privacy and the right to be protected from discrimination, can and should be applied to the treatment of all diseases. Based on the assumption that health practitioners do not perform any procedure or any test without engaging with their patient about the need and usefulness of such procedure or test, and that the same would only be undertaken once the patient has agreed, we argue that the same principles and procedures to be applied in the context of HIV and AIDS.

It is in this spirit, that as human rights activists, we, the Botswana Network on Ethics, Law and HIV/AIDS (BONELA), were initially very excited about routinely offering HIV tests at health facilities. In our minds, this should and could have happened a long time ago. In 2003, BONELA organised a consultative meeting with government officials, NGO activists, development partners and people living with HIV and AIDS to discuss this new approach. The meeting agreed that a routine offer for an HIV test should be made at all points of entry to the health system, but that patients needed to give their informed consent to such a test. This approach was based on the understanding that it is imperative to up-hold the patient's right to autonomy, and the right to make decisions about his or her body. However, the actual policy that has now become practice in Botswana is based on an 'opt-out approach', which does not require the patient's expressed informed consent.

In the current set-up it seems doubtful that patients understand their right to opt-out of an HIV test, especially considering the existing

power imbalances between the healthcare worker and the person accessing healthcare in public health facilities.

The lack of information about the right to opt-out of the HIV testing procedure also became apparent during research for a legislative review undertaken for the National AIDS Council. The researchers noted that

*...it is regrettable to note that from discussions we had with key informants, it emerged that public health practitioners do not in general do enough to inform patients about their right to opt out of routine testing.<sup>2</sup>*

In many of the debates about HIV testing, one of the missing links seems to be the societal context in which the testing is taking place, including the fact that provider-initiated HIV testing has a disproportionate impact on women, since women are the ones who have more contact with the health system, especially through ante-natal healthcare services.

The societal context is also characterised by stigma and discrimination in the context of HIV and AIDS. While HIV-related discrimination prevails, Botswana has, to this day, not enacted any legislation that protects the rights of people infected with HIV. For BONELA, running a legal aid clinic, it is a distressing reality to see on average two clients a day with complaints, such as unfair dismissal, refusal of employment and unfair treatment at the workplace due to a person's HIV positive status. In actual fact, Botswana has a Court of Appeal Judgment that pronounces it legal for employers to test for HIV, as a prerequisite for employment, and that it may be the decision of the employer not to employ applicants who test positive for HIV. This Court of Appeal Judgment has never been challenged and no legislation has been introduced to react to it.

Government often responds to the lack of a legal framework by pointing at the existing supportive policies which are in place. However, the same court noted that the Botswana HIV/AIDS Policy

*...had never been translated into law*

*and had no statutory authority. While it had strong moral persuasive force, [the employer] was not bound to follow it and had the right to make its own decisions regarding recruitment and its requirements in respect thereof.<sup>3</sup>*

The many calls of civil society to rectify the lack of adequate legislation have, thus far, not resulted in the pronouncement of such legislation.<sup>4</sup> As a result of a lack of protective labour legislation, it continues to be difficult for people living with HIV and AIDS to have access to, and/or remain in, employment, so as to be in the position to sustain themselves and their families.

There are other parts of the legislative framework that question whether or not Botswana has created an enabling and protective environment for people living with HIV and AIDS. For example, Botswana has adopted the concept of 'shared confidentiality', which severely limits, and at times violates, a person's right to privacy. And, as in so many other countries, laws protecting women from domestic violence and marital rape have not been passed in Botswana yet.

Why am I saying all of this? Would my argument be that if such protection and anti-discriminatory legislation would be in place, I would agree with HIV testing without informed consent? No, I would not, because I believe that people should be part of the decision-making process of their healthcare, since, it is only as and when people are agents of their own destiny, in an environment that protects and respects their human rights, that there will be a real change to the HIV epidemic in Botswana. A top-down government approach to the epidemic does not facilitate a process in which people take responsibility for themselves.

One of the arguments often brought forward by healthcare workers in Botswana is the fact that people were not coming forward to access treatment in the numbers that were expected and that people who accessed health facilities, and who were initiated on treat-

**...it may be the decision of the employer not to employ applicants who test positive for HIV...**

ment, presented themselves late and, therefore, the health system had to invest more time and money into their care. This argument raises a number of questions, including why it has been so difficult for the Botswana Government to make civil society true partners in the HIV testing efforts and, hence, initiating HIV testing facilities in NGOs, at community centres, in youth clubs etc? Would we not have made the

**...it is only as and when people are agents of their own destiny, in an environment that protects and respects their human rights, that there will be a real change to the HIV epidemic in Botswana...**

same impact in terms of the number of people coming forward for HIV testing, if we had increased the places where people can access voluntary counselling and testing? Who evaluated the HIV testing and counselling procedures and why did we not choose to improve the counselling standards to ensure that people would feel comfortable to test? If the problem has been the way that people were counselled, which, in actual fact, were scaring people away from the HIV test, why did we not radically change the counselling standards and procedures?

In conclusion, we need to ask ourselves: Testing to what end? Do we have evidence that people who have not consented to their HIV test, do actually live positively, protecting themselves from re-infection or infection, going onto ART and adhering to it? Is knowing one's HIV status synonymous with positive behaviour change and seeking care and support? It seems that people have recently engaged in a numbers game; pointing at the increase in HIV testing, but not qualifying such numbers with data about the actual impact that this has in terms of the wider response to the epidemic.

All of this seems to highlight that there is a definite need for independent research and monitoring of 'routine testing programmes', involving people living with HIV and AIDS and NGOs to understand the actual results coming from such programmes. And perhaps what all of us need to refocus on is; how do we enable people to make informed and conscious choices and, thus, to become agents of their own destiny.

**FOOTNOTES:**

1. An earlier version of this paper has been presented at the 2006 International AIDS Conference in Toronto, Canada.
2. Molatlhegi & Associates. November 2005. 'Consultancy Services to Review Laws and Policies relating to HIV/AIDS. Draft Final Report submitted to the National AIDS Council Sector on Ethics, Law and Human Rights'. Gaborone, Botswana.
3. Botswana Court of Appeal, Civil Appeal No. 27 of 2003 at 6-7.
4. It may be noted that a draft bill on employment is available but has not yet found government support.

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# Scale-up of HIV Counselling and Testing: A call for approaches based on human rights and gender equity<sup>1</sup>

## CONTEXT

To know one's HIV status is a part of the human right to health; it should not be a duty imposed on individuals by the State. For example, it is widely acknowledged that governments cannot oblige people to undertake genetic testing to determine if they are carriers of haemophilia or impose mandatory testing for genital herpes or hepatitis. Today, however, some governments and international agencies are pressing for changes to HIV testing strategies that can severely erode the rights of individuals to make informed choices about HIV testing and place control over these decisions in the hands of the State and the health care system. The ATHENA Network Steering Committee members unequivocally support the right of all individuals to know their HIV status, when and if they choose to be tested, and to have easy and affordable access to voluntary HIV counselling and testing (VCT) services. We also support scaling up the routine offer of opt-in HIV testing and counselling within healthcare systems, with the primary aims of enabling people who test HIV positive to access adequate support, care and treatment and supporting people who test HIV negative to take measures to maintain that status.

We recognise that, as treatment access improves, more individuals will want to know their HIV status. We are, however, increasingly concerned about the direction and nature of international and national debates regarding universal testing for HIV infection. While VCT was promoted as the HIV testing strategy of choice until recently, there is currently a move toward routine opt-out testing in many diverse settings worldwide, even when the people tested will not have access to support, care and treatment. In some cases, this has translated into proposals for, and implementation of, routine imposition of HIV tests. We recognise that international agencies are currently re-assessing their recommendations on HIV testing and counselling and we wish to contribute to this process by outlining what we think must be taken into account at a minimum.

## OUR PROPOSED FRAMEWORK

We call for all approaches to HIV testing to be based first and foremost on basic ethical principles.

- The principle of **beneficence** demands that HIV counselling and testing should maximize the best health outcomes for *individuals* and communities.
- The principle of **nonmaleficence** (do no harm) requires that

HIV testing programmes include measures to prevent and effectively deal with negative repercussions for people who test positive for HIV, including stigma, discrimination and gender-based violence.

- The principle of **autonomy** means that people must be enabled to make informed choices about their own healthcare, including whether or not to voluntarily test for HIV.

We further **insist that HIV testing programmes be based on full adherence to, and support for, human rights, which are interdependent and indivisible.**

- The **right to security of person** ensures that people are entitled to decide for themselves whether or not to have an HIV test; neither the government nor healthcare providers should pressure people to do so.
- The **right to health information** means that pre-test counselling/information must include a review of both the benefits and possible negative consequences of HIV testing (for example, including, but not limited to, availability and costs of antiretroviral treatment (ART), availability of measures to prevent perinatal transmission, possible consequences for health and other insurance, possible consequences of stigma and discrimination in relation to education, employment, housing and immigration).
- The **rights to informed choice and informed consent** imply that HIV testing protocols and training of people who offer pre-test counselling/information must stress measures to

ensure that clients/patients know they may refuse a test without compromising their further healthcare, and that clients/patients receive the information in a language and wording that they can easily understand.

- The **rights to privacy and confidentiality** mean that healthcare providers must pay special attention to ensuring that people's decision to test for HIV and their HIV test results are not disclosed to third parties without their consent.
- The **right to health** implies that people have access to health systems with adequately resourced HIV testing protocols (for example, not only with money for rapid tests, but also money for sufficient counsellors and referral centres); adequate logistical resources to ensure privacy, confidentiality and sufficient time to make informed decisions; adequate funding to manage human resources and logistics; and, the right to receive treatment and referrals to services and support networks, if needed after testing HIV positive.

### ...we must challenge the assumption ... that HIV testing stands as a primary means of HIV prevention until a vaccine becomes available...

- The **right to the benefits of scientific progress** means that HIV testing and counselling must be offered in conjunction with affordable and accessible antiretroviral treatment and therapies for opportunistic infections.
- The **obligation of States to progressively realise the right to health** implies that they must formulate

indicators to measure such progress and provide accountability regarding HIV testing programmes to all relevant stakeholders.

Lastly, we insist that **the development, implementation, monitoring and evaluation of HIV testing policies and programmes be transparent and that means of accountability be ensured.**

This requires:

- The **meaningful participation of civil society representatives from all affected and potentially affected communities** in the development, design and implementation of HIV testing policies and programmes.
- The **central involvement of, and consultation with, people living with HIV**, who intimately know the needs resulting from receiving a positive HIV diagnosis.
- The inclusion of these aforementioned representatives in shaping and carrying out the monitoring and evaluation of programmes as they are implemented.

### WHAT IS AT STAKE

We must challenge the assumption – now rife in international debates about HIV testing – that HIV testing stands as a primary means of HIV prevention until a vaccine becomes available. In this call to action, we ask to express support for the above-mentioned framework of ethical principles and human rights as the context for HIV testing and counselling.

Below, we briefly describe the reasons for our concern. The human rights and public health concerns overlap and are inextricably linked.

Proponents of routine, provider-initiated opt-out HIV testing programmes are driven by laudable-sounding motives. For example, it is presumed that people who know their HIV status will be better able to change their behaviour, if necessary; it is also assumed that mass testing will 'normalise' HIV and AIDS, by reducing stigma and discrimination, and help people gain access to treatment. These claims are problematic:

- **There is no evidence that increased HIV testing leads to increased behaviour change to prevent HIV transmission, nor is there evidence that more testing de-stigmatises HIV.** On the contrary, the evidence shows that it is increased availability of treatment, care and support and increased de-stigmatisation of HIV and AIDS that can lead to more people wanting to know their HIV status. An enabling environment that ensures people have access to life-prolonging treatment, changes social acceptance of HIV infection from a 'death sentence' to a chronic condition. Decreasing fears about HIV can also help reduce tendencies to associate HIV infection with 'immoral behaviours', which often especially impact women and non-heterosexual persons.
- In many places, **ART is still only available to a small percentage of HIV infected persons who need it.** Asking or demanding that people test for HIV without offering the benefits of ongoing treatment as needed is unethical. This is particularly



the case for women who are only offered ART to prevent perinatal transmission, but not to ensure their own survival after giving birth.

- **Gender-based violence** is already rampant. Violence is both a precursor to high rates of HIV infections, as well as a consequence of assumed or confirmed HIV positive status. Yet few, if any, steps are being taken to integrate efforts to address violence as a part of routine HIV testing programmes.
- Many women, particularly when they are the first in a couple to test, as is often the case with antenatal HIV testing, continue to be subjected to **gender-based stigma** and **discrimination**. Women face blame, assault, loss of employment, loss of child custody, divorce and/or eviction from their homes. In addition, their subsequent treatment may be jeopardised by partners who refuse testing for HIV, but steal their drugs.

## ...demanding that people test for HIV without ... treatment ... is unethical ... particularly ... for women who are only offered ART to prevent perinatal transmission, but not to ensure their own survival after giving birth...

The rapid scale-up of routine opt-out HIV testing without a clear right of refusal, fully informed consent, accompanying counselling and strict measures to protect confidentiality will undermine public health and may exacerbate violations of basic human rights.

- Policy makers now talk about the *'informed right of refusal'*. However, in practice this may become forced HIV testing, due to power imbalances between healthcare providers and clients. **Women, especially, often don't dare say no because of gender-based reinforcement of their subordinate position in society.**
- Women who are tested for HIV or *'offered'* an HIV test during labour and delivery are burdened with the need to decide during a time of stress, such that they are prevented from giving truly informed consent and, if tested HIV positive, from effectively dealing with the implications of a positive HIV test result. It is **unknown what impact this has on women's decisions related to postnatal care.**
- **The fear of being pressured into having an HIV test may prevent individuals from seeking needed medical care.**
- **The basic right to information may be violated.** Limiting pre-test counselling leaves individuals ill-prepared for a positive

HIV diagnosis and represents the loss of a critical opportunity to provide prevention and care to the many who will not return, because they were unprepared to test for HIV in the first place or felt coerced into testing.

- **Breaches of confidentiality are likely** if the need to rapidly *'process'* increased numbers of HIV tests is taking place in the absence of strenuous efforts to improve the healthcare infrastructure and adequately train healthcare providers and counsellors. Positive HIV test results should not be communicated where third parties can overhear, recorded on documents third parties can read or revealed to others without the client's consent (e.g., spouses, in-laws, employers).

Approaches to **HIV testing must be a part of a continuum of action to fulfil basic human rights and of broader efforts to advance health.** This requires that we can only prioritise HIV testing as part of meaningful efforts to scale up HIV prevention, treatment and care. Implementing a **rights-based approach to HIV testing scale-up is necessary for public health policy to be sound and for our response to the epidemic to be effective.**

### FOOTNOTES:

1. This document is a working paper, under development by input from ATHENA Network members, and a call for global consultation and input. This document has been developed in September 2006.
2. For more information on the ATHENA network go to [www.athenanetwork.org](http://www.athenanetwork.org).

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# Opt-out routine HIV testing – a flawed strategy

For years, testing for HIV has been based on the Voluntary Counselling and Testing (VCT) model. From early 2004, Botswana, which is hailed as an ideal, had actively adopted opt-out routine HIV testing in its programme. In June 2004, UNAIDS recommended the routine offer of HIV testing based on the Botswana model. This model is now being followed in other countries including Kenya, United Kingdom and some places in the United States, in particular San Francisco.<sup>1</sup> The current US Centre for Disease Control (CDC) and WHO recommendations too reflect this.<sup>2</sup>

The change was heralded not only because of the basic change in the treatment scenario of HIV, the success of the triple combination therapy from 1996, but more fundamentally on account of the availability of cheap supply of first line generic ARV drugs, primarily from India. However, it may be pointed out that some commentators have gone as far as stating that:

*Current guidelines restrict the use of routine testing to settings in which antiretroviral therapy is available. We believe that the recommendations should support routine testing wherever basic HIV care and prevention are available. [De Cock et al. 2006:440]*

What is the opt-out routine HIV testing model? Basically, nearly all patients are tested for HIV as a routine part of medical visits, unless they explicitly refuse. In contrast to the VCT model, there is very little or no emphasis on pre-test counselling. In addition, all patients should receive essential information about HIV and be informed about the right to refuse.<sup>3</sup> Moreover, consent is effectively done away with.

There is quite an active debate on this issue. Let me attempt to summarise its contours.

Firstly, it is the case of the proponents of opt-out routine HIV testing that the pre-test counselling model that had been adopted earlier in the HIV epidemic may have been valid in the era when there was no treatment available. However, now that treatment is available, the pre-test counselling model is redundant. Secondly, in the context of availability of treatment, it is important that people test for HIV so that treatment is made available to them. Thirdly, pre-test counselling takes a lot of time and resources that are better utilised for HIV testing. Fourthly, it has only created HIV and AIDS exceptionalism, which has only fuelled the societal stigma around HIV. Finally, as a result, pre-test counselling has dissuaded persons from taking an HIV test or created a barrier or impediment to HIV testing and, therefore, the very delivery of treatment.

There is indeed a need for extensive debate on this issue. Therefore, let me also add a few points that I think are important in this very vital debate.

Undoubtedly, the vast majority of people living with HIV, do not know that they are infected with HIV. It is in their interest to know that they are indeed infected with HIV, so that they can protect themselves by taking appropriate treatment and also protect others. Therefore, scaling up of HIV testing is of the utmost necessity. There can be no two opinions on this proposition. The real question is how this should be done and whether or not opt-out routine testing for HIV is the best option globally in the circumstances that obtain today or in the near future. Questioning the modalities of opt-out routine testing does not in any way detract from the commitment to universal access to treatment.

## **Universal ART access is not possible throughout the world**

It is clear that the opt-out routine HIV testing model is conditional on the universal access to treatment. Unfortunately, with all my optimism on all issues, I am apprehensive that universal access will not be a reality in the near future for the vast majority of people living with HIV in developing countries.

At the global level, the 3 by 5 initiative was able to reach only approximately 50% of its target by 2005.

In India, where the estimate of people living with HIV in 2006 is nearly 5.2 million in the adult population (15 to 49 years), anywhere from 500,000 to 780,000 require ART<sup>4</sup>. However, the Government of

India's target is to provide free first line treatment to only 188,000 and that too only by 2010, and 300,000 by 2011. The actual number of people on ART, as of August 2006 is 36,000. As yet there is no provision for the second line drugs that will be increasingly required.

Most of the funding for the provision of ARV drugs comes from the Global Fund. According to the UN 2006 Report on the Global AIDS Epidemic, the funding gap for Global Fund is US \$6 billion in 2006 and will increase to US \$8.1 billion in 2007.<sup>5</sup> Huge efforts have to be made to close this gap.

What this means is that ARV treatment may not be available to a vast majority of people living with HIV. In that case the opt-out routine HIV testing model is not really a practical option at all.

### The principles of consent need to be protected and promoted

My other concern with opt-out routine testing for HIV is the fact that it does away with consent, which is a precious human right.

The law in common law countries, (i.e. English speaking and the

## ...proponents of opt-out routine HIV testing ... [claim] ... that the pre-test counselling ... may have been valid in the era when there was no treatment available ... now that treatment is available, the pre-test counselling model is redundant...

erstwhile British Commonwealth), is quite clear. As the US Supreme Court judge, Justice Cardozo, put it in his classic statement,

*Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation on his patient without his patient's consent commits an assault, for which he is liable in damages.*<sup>6</sup>

This proposition has been accepted in common law jurisdictions that have held that every person's body is inviolate.<sup>7</sup> The exceptions are limited to emergencies, persons who are not conferred the legal capacity to consent (who are not of 'sound mind' or people who are minors in law) when the doctrine of necessity may come to the rescue of the healthcare provider. In *JWB and SMB* case, Justice Brennan of the High Court of Australia pointed out that international human rights instruments also adopt the same principles. On that basis, he held that human dignity required the protection of the physical integrity of a human being.<sup>8</sup>

The necessity of taking consent cannot be restricted to treatment only, as it also applies to diagnostic testing. Significantly, it has been

held by the House of Lords in England that, 'there is no doubt that a person of full age and capacity cannot be ordered to undergo a blood test against his will'.<sup>9</sup> The House of Lords added a warning, which is relevant for our purposes and said:

*The real reason is that English law goes to great lengths to protect a person of full age and capacity from interference with his personal liberty. We have too often seen freedom disappear in other countries not only by coups d'etat but by gradual erosion, and often it is the first step that counts. So it would be unwise to make even minor concessions.*<sup>10</sup>

As Justice Brennan, in the case of *JWB and SMB*,<sup>11</sup> pointed out, such principles are now adopted in international humanitarian law. Do we need to sacrifice such important principles, adopted by domestic and international law, for scaling up HIV testing? I would respectfully submit that such principles cannot be sacrificed easily. At the minimum, there must be compelling reasons to do so. Are scaling up of treatment and the Botswana model compelling enough reasons? That is the key question.

The doctor-patient relationship is inherently unequal for reasons of knowledge, skill that the doctor possesses and trust reposed by the patient in the doctor. The opt-out routine HIV testing model wrongly assumes that everyone is equally empowered. With such inequality, will the patient be able to refuse even if she or he is informed of her or his right to refuse?

Necessary information is given to the patient to enable her or him to give consent. The skill that the doctor possesses and the trust reposed by the patient remains intact though modified. However, knowledge is imparted. The information assists the patient to make a decision.<sup>12</sup> Though consent has been well-rooted in the common law tradition, informed consent is of recent origin. Most jurisdictions now accept that consent means informed consent and it implies at least informing the patient about the benefits, risks and alternatives. From

*Canterbury v Spence*<sup>13</sup> in the US, it has traversed through *Riebl v Hughes*<sup>14</sup> in Canada, and to an extent accepted in *Pearce v United Bristol Healthcare Trust NHS*.<sup>15</sup> The trend is clear. Even outside the context of HIV, the trend has been to adopt informed consent principles.

While in developed countries informed consent is well-rooted not only in the law, but

**...the vast majority of people living with HIV, do not know that they are infected... it is in their interest to know ... so that they can protect themselves ... and also protect others....**

also in practice, more particularly in the healthcare setting, that is not the case in most developing countries.

In India for instance, as is the case with a lot of the erstwhile Commonwealth countries, the principles of consent developed in the common law of England are readily followed by judicial authorities. However, these principles are not strongly rooted at the field level in the healthcare set-up. Thus, for example, consent is a formality in case of admission to a hospital and surgical interventions in India. Consent is not really voluntary. Informed consent in the healthcare setting is not a reality even in major interventions outside the context of HIV.

It is in this context that HIV came on the legal scene in India and perhaps in a lot of the developing countries. The HIV epidemic in developing countries, in one sense, provided an opportunity to reaffirm the principles of consent and confidentiality and try to firmly

root them in the healthcare set up. Most of our advocacy efforts in the last ten years have been to promote and protect these principles in the healthcare system. I would say that we have achieved some measure of success. However, given that these require a change in the mind-set of the healthcare provider, who is most interested in getting a job done, it has been a long haul with a lot of resistance. Ironically, one of the factors that assisted us in the advocacy to reaffirm these basic principles was the lack of treatment for HIV and the enormous stigma associated with it. We are a long way off from getting these principles accepted in practice at the ground level. In this scenario if opt-out routine HIV testing is recommended globally, the clear message for all the medical fraternity in the developing world would be to test all persons for HIV, without consent, i.e. mandatory testing.

Even the proponents of opt-out routine HIV testing fear that such a policy may turn out to be coercive. Thus, De Cock et al [2006:441] has this to say:

*Careful guidance is required, however, to determine how to implement such testing without coercion and how to limit the negative social consequences of a pre-marital diagnosis of HIV infection, especially for young women.*

I fear that in most developing countries implementation of the HIV test will in fact be with coercion.

#### **Botswana cannot be the only model**

The opt-out routine HIV testing model is largely based on the experience in Botswana. What is the experience there? According to Alexander Jarvis, in a study of antenatal clinics in Botswana's second city, Francistown, an increase in uptake of women testing for HIV from just over 75 percent in the last four months of the VCT approach to 90.5 percent in the first three months of the new policy of opt-out routine HIV testing was found.<sup>16</sup> But compared to other countries, one realises, that it is not a great jump. What are the figures for India? In 2005, across India, nearly 1,134,839 had registered on the PMTCT programme. 88.13% of the people counselled in the PMTCT programme went in for the HIV test.<sup>17</sup> Another case in point is Uganda, where 95% of people who were counselled in home visits agreed to test for HIV. Of these, 88% were first-time testers.<sup>18</sup> Therefore, Botswana does not appear to be a case that needs to be followed globally.

#### **Can we do something about the counselling?**

Apart from jettisoning effective consent the other change in opt-out HIV testing is to effectively do away with pre-test counselling.

**I fear that in most developing countries implementation of the HIV test will in fact be with coercion.**



Counselling strategies were developed in the era when treatment was not available to the people living with HIV. Pre-test counselling prepared a person, not only for the HIV test, but also for the consequences of coping with a positive test result without any treatment. It could not have possibly prepared one for treatment that became available later. As the treatment scenario changed in the HIV context, both in terms of triple combination being found effective and the drugs becoming affordable and accessible, protocols for counselling, both pre-test and post-test needed to be overhauled drastically. However, that does not appear to have been done.

It is well documented that although the process of counselling was changed over a period of time, the content did not change to include information about availability of treatment even after treatment became available.<sup>19</sup>

What about Botswana? Why were people in Botswana not going for HIV testing? One would expect that a person informed of the benefits of testing for HIV, would opt for testing. Undoubtedly, fear of stigma is a factor that dissuades a person from testing for HIV. Was the healthcare system in Botswana not tackling stigma? What about HIV counselling in Botswana? Was there a problem in the content of pre-test counselling or in the way that it was administered? In a report according to Dr. Howard Moffat, medical superintendent at Princess Marina Hospital in the capital, Gaborone, 'People who were not sure they wanted to know their HIV status often emerged from counseling determined not to be tested'.<sup>20</sup> He added: 'I think the medical profession itself ... played a major role in creating this fear of AIDS and this quite irrational reluctance to be tested'.<sup>21</sup> According to the same report: 'Doctors here believe pulling patients aside for special counseling is intimidating and helps fuel the stigma that keeps patients from seeking help'.<sup>22</sup>

It appears, therefore, that the manner in which counselling was being administered in Botswana raises a lot of concerns. We do not know about the content of counselling. But it appears that it was the pre-test counselling that pushed persons away from testing for HIV. Thus, pre-test counselling, which was meant to help people living with HIV to cope with life, had become a tool of terror in the hands of the healthcare providers. If that be the case, one can hardly come to the conclusion that pre-test counselling in the manner that it is to be actually administered has become an impediment.

In these circumstances, I would submit that serious issues arise about the content of counselling and the manner that it is to be administered. Certainly it does not warrant a global strategy of HIV testing based on the Botswana model of opt-out routine testing.

### How do we ensure non-discrimination?

All the proponents of opt-out HIV testing articulate that the model should be adopted on the basis of certain guarantees and/or assurances. De Cock et al [2006:442] states:

*We recommend routine testing for HIV for persons in key occupations, with guarantees of confidentiality, protection*

**...unfortunately, it is impossible to control stigma, because it operates in silent, secretive and subversive ways. The law only steps in much later, after the event, after the damage has been done...**

*against discrimination, free treatment for infected persons, and post-exposure prophylaxis as appropriate.*

Edwin Cameron states:

*There must be some assurance that the consequence of diagnosis will not be discrimination and ostracism; and the patient should be secure that the testing procedure and its outcome will be treated as confidential.*<sup>23</sup>

It is difficult to understand how these guarantees or assurances would, especially in the context of pervasive stigma, have any meaning in real terms. Unfortunately, it is impossible to control stigma, because it operates in silent, secretive and subversive ways. The law only steps in much later, after the event, after the damage has been done. Even then, at best, it compensates the individual in monetary terms, but cannot restore the damage that is caused to the psyche of an individual.

The real challenge is to control stigma within communities and within individuals. We should focus our energies on that. What we need is a massive investment in programmes to de-stigmatise HIV and make people living with HIV acceptable in society. With such general awareness, the content of pre-test counselling has to change, making an

**...pre-test counselling is essential not only because it is the only entry point of information for persons who may test HIV negative, but also for people who test positive for HIV so that messages of HIV prevention, safety, treatment availability and adherence are imparted...**

HIV test a positive step to be taken, rather than frightening the person away from it. Pre-test counselling is essential not only because it is the only entry point of information for persons who may test HIV negative, but also for people who test positive for HIV so that messages of HIV prevention, safety, treatment availability and adherence are imparted. The more that ART becomes the norm, the more the money and resources that will have to be spent on counselling, even post-test counselling. Pre-test counselling will become a routine part of the counselling continuum.

It is in this context that I would respectfully disagree with Edwin Cameron who, while supporting opt-out routine HIV testing, has made the point that though pre-test and post-test counselling are both useful, they should not be carried out at the expense of draining away time and energy of healthcare personnel, whose priority should be diagnosis, testing and treatment.<sup>24</sup> The point is not of pitting one against the other, but viewing pre-test counselling as an essential aid to HIV testing.

Thus, with ART becoming increasingly available, what we need is to protect and promote pre-test counselling and informed HIV testing, preserve confidentiality and, thereby, reduce discrimination. That will ensure a non-discriminatory environment which would help to move towards universal access.

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4. While the National AIDS Control Organization (NACO) estimated that 500,000 people living with HIV need ed treatment, UNAIDS estimated the number to be 780,000.
5. UNAIDS. 2006. *2006 Report on the Global AIDS Epidemic*. Chapter 10, p. 249.
6. *Schloendorff v Society of New York Hospital*, 211 NY 125, pp. 129–130 (1914).
7. In England: *Sidaway v Governors of Bethlem Royal Hospital*, [1985] AC 871, *St. George's Healthcare NST v S*, [1998] 3 All ER 673 (CA); In Canada: *Reibl v Hughes*, [1980] 2 S.C.R. 880 : (1980) 114 DLR (3d) 1, *Mallet v Shulman*, (1990) 67 DLR (4th) 321 (Ont CA); In Australia: *Secretary, Department of Health v JWB and SMB*, [1992] HCA 15 : (1992) 66 ALJR 300.
8. *ibid.*
9. *S v S*, [1970] 3 All ER 107.
10. *ibid.*
11. *JWB and SMB*, *supra* note 7.
12. Gostin, L. 1990. 'The HIV Infected Health Care Professional: Public Policy, Discrimination, and Patient Safety'. In: *Law, Medicine and Health Care*. 18(4), 303–10.
13. 464 F.2d 772 (DC Cir. 1972).
14. *Reibl supra* note 7.
15. [1998] EWCA Civ 865 (20 May 1998) : (1998) 48 BMLR 118 (CA) (basing the doctor's obligation to inform on the significant risk to the patient).
16. Zavis, A. 2006. 'Botswana adopts new approach to HIV tests'. Courtesy *South African Press Association*, 5 January 2006. (<http://ww4.aegis.org/news/sapa/2006/SA060102.html>)
17. UNGASS India Report, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, New Delhi, 2005, ([http://data.unaids.org/pub/Report/2006/2006\\_country\\_progress\\_report\\_india\\_en.pdf](http://data.unaids.org/pub/Report/2006/2006_country_progress_report_india_en.pdf))
18. 'High discordance rates among Ugandan ART clients new prevention approaches'. *AIDSMAP News*. (<http://www.aidsmap.com/en/news/0619D2A9-1319-41D6-8515-244E05F2B60F.asp>)
19. Sheon, N. 2004. 'Theory and Practice of Client Centered Counseling and Testing'. Center for AIDS Prevention Studies, University of California, San Francisco, HIV Insite Knowledge Base Chapter. Reviewed in January 2006, (<http://hivinsite.ucsf.edu/InSite?page=kb-07-01-04>). See also 'HIV Counseling and Testing'. In: *Family Health International*. (<http://www.fhi.org/en/Topics/Voluntary+Counseling+and+Testing+topic+page.htm>)
20. Zavis, A. *supra* note 16.
21. *ibid.*
22. *ibid.*
23. 'AIDS: Building on Hope and Reason'. (Speech delivered by Justice Edwin Cameron, Judge, Supreme Court of Appeal at South Africa, Bloemfontein, at Oxford University on 23 June 2006).
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# HIV Testing: An effective prevention measure?

## INTRODUCTION

Statistics<sup>1</sup> indicate that there is a high HIV infection rate in South Africa, with 18.8% of the population living with HIV, and high daily rates of new HIV infections. In light of these statistics, HIV prevention is of vital importance, and large amounts of resources have been allocated to HIV prevention, yet, South Africa, and countries all over the world are seemingly struggling with effective prevention measures.

It is important to note, that HIV prevention measures need to be distinguished from HIV prevention. HIV prevention is the individual choice a person makes on whether or not to prevent, and/or minimise the risk of HIV infection, including the choice whether or not to abstain from sex and/or to use a condom. HIV prevention measures could be considered as the structural or environmental factors influencing the extent to which people are in the position to make these choices. These factors range from basic things, such as access to condoms and information, to the broader issues of inequality, stigma and discrimination impacting on individual choices and the extent to which available services are accessible.

If HIV testing could be argued to be an effective prevention measure, then it would be necessary that testing, like other HIV prevention measures, adhere to fundamental human rights principles. UNAIDS<sup>2</sup> identifies a number of key factors that would ensure that human rights principles are applied appropriately in the context of HIV testing, stressing the voluntary nature of testing. These principles include that there needs to be an *'ethical process'*, including information, links to treatment, care and services and the absolute confidentiality of medical information; that testing processes need to address the *'implications of a positive test result'*, including access to treatment and care; the reduction of HIV and AIDS related stigma and discrimination, especially in healthcare settings; making sure that there is a *'supportive legal and policy framework in place which assists in ensuring the human rights of people seeking tests and treatment; and making sure that there is adequate healthcare infrastructure, including trained staff to deal with an increase in the demand for HIV related services.*

In light of these principles, this article seeks to explore the theory that HIV testing can be an effective prevention measure and to assess various arguments for and against this theory. Questions raised in this article will include whether or not voluntary counselling and testing (VCT) is indeed a means of HIV prevention; whether or not VCT upholds the rights of people to make free and informed choices regarding the prevention of HIV infection; and whether or not VCT does contribute in any way to people making choices that would reduce the risk of HIV infections.

## IS TESTING AN EFFECTIVE PREVENTION MEASURE?

The UNFPA policy statement on VCT for HIV prevention<sup>3</sup>, states that VCT is an essential part of efforts to raise public awareness about HIV and AIDS, and to reduce stigma and discrimination, but makes no mention of how this will happen. UNFPA strongly supports VCT *'as an effective strategy for facilitating behaviour change around both preventing HIV and early access to care and support'* (UNFPA statement). In addition, the UNAIDS Policy Statement on HIV Testing<sup>4</sup> also emphasises HIV testing as an intervention that plays an important role in HIV prevention.

This theory seems to be based on a number of assumptions. Thornton [2005:1] highlights that people will find benefit from knowing their HIV status; that social barriers, such as stigma and discrimination, stop people from finding out their HIV status; and that if people know their HIV status, it will have a positive impact on people's behavioural choices towards safer sex. It is this last assumption that seems to drive the idea that HIV testing is a prevention measure.

According to Anderson (2006):

*...many studies indicate that VCT has been proven to be effective in reducing high-risk behaviour and subsequently the spread of HIV. A study in Central Mozambique showed that participants in VCT reported a significant increase in condom use after VCT. Similarly in a study of VCT programmes in Cape Town Townships, evidence showed that VCT can result in behaviour change and can improve coping strategies of people with HIV, by reducing risk behaviour.*

This assertion is confirmed by Lamb et al (1998). The study, conducted in the US in the late 1990's, compared risk reduction behaviour in people who were given

counselling interventions with people who were given didactic prevention messages and concluded that

*...short counseling interventions using personalized risk reduction plans can increase condom use and prevent new STD's. Effective counseling can be conducted even in busy public clinics.*

Nieburg et al (2005) also support the notion that HIV testing will make a substantial contribution to reducing the number of HIV infections. Further evidence for this is cited by Anderson (2006), where data indicated that the knowledge of one's HIV status reduces the risk of sexual HIV transmission by 68%. Since HIV testing in South Africa follows the VCT approach and, thus, includes counselling and basic information about HIV transmission and prevention, it could be argued that VCT does indeed have the potential to contribute to HIV prevention. However, there is only limited data available supporting this argument, and the data available, identifying HIV testing as an effective prevention measure, is not widely validated, and when it is, questions are raised

**...the evidence seems to indicate that HIV testing has little or no impact on behavioural change that would lead to reduced risk of HIV infection...**

as to whether or not the methodology of data gathering makes it possible to generalise the data.

In this context, Thornton [2005:2] points out that the methodology for data gathering in support of the view that HIV testing contributes towards HIV prevention is problematic, since the participants are self-selected and the data usually relies on self-reported sexual behaviour. That self-reported sexual behaviour data is often unreliable is also supported by a study in which 15% of women participating, who reported that they were using condoms 100% of the time, had

**...the proportion of people who have been for an HIV test, accounts for no more than 10 percent of the number of people who are estimated to be HIV positive...**

sperm present when a vaginal smear test was done<sup>5</sup>. Thus, there remains doubt regarding whether or not these studies could be used as conclusive proof that HIV testing does in fact work as an effective prevention measure.

The evidence for viewing HIV testing as an effective HIV prevention measure looks, in fact, pretty slim and there are research findings<sup>6</sup> asserting that HIV testing, and specifically VCT, have no real impact on the prevention of HIV transmission at all. In one review of HIV testing as a prevention measure for a large funding agency, Alcom [2005:3-4] cites evidence from trials indicating both support for the notion that VCT contributes to behavioural change towards safer sex and, therefore, a possible decrease in the levels of HIV infection, as well as support for the notion that VCT interventions have limited or no impact on behavioural change.

There are, however, a few sources<sup>7</sup> indicating that for people who test positive for HIV, the HIV test result had an impact on sexual behaviour in terms of people choosing safer sex options. For people who test negative for HIV, there is no supporting data that shows any change in sexual behaviour, compared to people who do not undergo an HIV test.

The evidence seems to indicate that HIV testing has little or no impact on behavioural change that would lead to reduced risk of HIV infection. An important question to be raised, while examining HIV testing as an effective prevention measure, is whether or not HIV testing promotes and facilitates informed choice, thereby upholding human rights principles. But there is no data available on this question in any of the studies surveyed. There is, however, data available clearly indicating that there is no specific measurable impact of HIV testing on safer sex choices. Exner's (2002) study in the US with women attending STI clinics shows that there was no correlation between going for an HIV test and any change in sexual choices around protected or unprotected sex. This is supported by a study in South Africa (Kalichman & Simbayi, 2003), which concluded that there was no real difference in the knowledge of HIV prevention between people who had been for an HIV test and people who have not been tested for HIV.

Alcom [2005:5] concludes that *'where prevention activities are limited and the primary investment has been in VCT, it is unrealistic to expect that behaviour change can be sustained'*. This view is supported by Handsfield (2006) who states that the limited intervention available through pre- and post-test counselling *'has had no measurable effect on patients' subsequent risk of acquiring HIV'*.

## CONTRADICTIONS AND CONCERNS

In addition to the contradictory evidence of whether or not HIV



testing provides any significant contribution as an HIV prevention measure, there are a number of other issues, raised in the research on HIV testing and prevention, that are important to consider.

One of these issues, raised by Exner (2002), is a high tendency, amongst study participants, to believe that regular HIV testing is an effective prevention method; in that regular HIV testing would minimise the possibility of HIV infection. Similarly, Kalichman and Sambiyi (2003) highlighted that more than half of the people surveyed believed that testing for HIV helps prevent HIV infection. This is further supported by Thornton [2005:24] who argues that *'receiving an HIV negative diagnosis significantly reduced the likelihood of believing there was a chance of being infected'*.

The belief that HIV testing is a prevention method, as in HIV testing will indeed prevent HIV infection, is, as can be argued, also factually inaccurate, since HIV testing can only have the potential to 'clear' a person of past risk to HIV infection, not future risk. Thus, this belief is rather disconcerting, especially if taken in conjunction with research findings indicating that testing negative for HIV does not contribute significantly to behavioural change, including safer sex behaviour. The above further seems to indicate that while access to information regarding sexual and reproductive health choices, through testing for HIV, may put all the elements in place needed for people to make informed choices, it has no significant impact on whether or not people choose to make safer sex choices.

In addition, the number of people accessing HIV testing is very low. According to Nieburg et al [2005:2], the proportion of people who have been for an HIV test, accounts for no more than 10 percent of the number of people who are estimated to be HIV positive. In South Africa, only one out of five people, who know that VCT is offered, actually take up the services.<sup>8</sup> This seems to raise questions around the degree to which studies, based on this small level of uptake, can in fact provide any conclusive evidence as to whether or not HIV testing could provide an effective prevention measure, and, arguably, raises the question as to further underlying factors influencing the choices people make.

## STIGMA AND DISCRIMINATION

Exploring some of the reasons why people do not access HIV testing services, Thornton [2005:2-4] argues that the cost of the service, the distance it takes to travel to get to the service, and gender dynamics all play a role in accessing testing for HIV. Thus, if a healthcare facility is not within physical or financial reach, it impacts on the extent to which people are in the position to access services. But even when facilities are more easily accessible, the rate of testing remains low. Various research studies<sup>9</sup> argue that this is due to the prevalence of stigma and discrimination towards people living with, or are perceived to live with, HIV and AIDS, which results in a general reluctance to test for HIV. According to Kippax [2005:8],

*...there is evidence that in many countries in the developing world, prevention in the context of VCT is creating personal and social problems for a substantial proportion of individual clients/patients.*

Anecdotal evidence suggests that the prevailing stigma and

**...if VCT is to become an effective prevention measure, HIV testing services would have to be widely accessible, widely used, free of stigma and discrimination, and based on informed choice...**

discrimination amongst service providers further contributes to this reluctance.

The prevalence of stigma and discrimination is, therefore, a barrier to the effective utilisation of HIV testing, as any kind of prevention measure. If stigma and discrimination pervade the attitudes of healthcare workers administering VCT, as much anecdotal evidence suggests, HIV testing does not provide the space for access to information that would enable people to make informed choices about HIV prevention. In addition, if knowing of a person's HIV positive status is likely to result, as argued by Nieburg et al [2005:4], in the aggravation of stigma, discrimination and risk of violence, especially for girls and women, then what would be the benefit of HIV testing, especially in settings, where the confidentiality of HIV test results cannot be adequately ensured, and how could HIV testing have an impact on HIV prevention? But even if access to HIV testing actually contributes to the decrease of stigma and discrimination, and this theory has yet to be proven, the question as to whether or not HIV testing impacts on individual choices regarding HIV prevention, still remains to be answered.

## CONCLUSIONS

Alcom [2005:4] highlights that

*The contradictory evidence on the HIV prevention benefits of voluntary*

*counselling and testing makes it difficult to determine the relative contribution of VCT to prevention of onward transmission and behaviour change...but longer-term and larger scale research into the effectiveness of VCT would be useful*'.

In other words, there are arguments both for and against seeing VCT as an effective prevention measure, but neither set of arguments or data offers conclusive evidence, despite the official adoption by UNAIDS and UNFPA of policy that promotes VCT as a prevention measure.

Even if the view is taken that VCT does have an impact as a prevention measure, it seems to be limited. Thus, concentrating on VCT as a prevention strategy will remain to be ineffective, if not integrated into a wider range of prevention strategies. These strategies need to include rights-based messaging and education addressing, amongst other things, stigma, discrimination and inequalities as barriers to HIV testing and prevention.

In addition to the education and messaging, the general human rights-based principles, outlined by UNAIDS, which include the voluntary nature of testing; an emphasis on non-discrimination and delivery of services in a legislative framework that ensures these rights are protected; and that adequate and sufficient resources are allocated to ensure adequate testing, treatment and care services, need to be guaranteed and in place. If these are ensured, there might be an uptake in people accessing HIV testing services, in which case the option of beginning to adequately research whether or not HIV testing carries the potential to contribute to behavioural change could begin to be explored.

If VCT is to become an effective prevention measure, HIV testing services would have to be widely accessible, widely used, free of stigma and discrimination, and based on informed choice – and maybe then HIV testing would contribute towards behavioural change and safer sex practices. Currently, evidence shows that it is stigma and discrimination that pose barriers to HIV testing, rather than a 'lack of perceived value of getting tested' [Kalichman & Simbayi, 2003]. Thus, as long as stigma and

discrimination are not adequately addressed, the belief that HIV testing could be an effective protection measure is nothing more than a theory with little or no impact on HIV prevention realities in South Africa.

#### FOOTNOTES:

1. UNAIDS. 2006 Report on the Global AIDS Epidemic.
2. UNAIDS/WHO Policy Statement of HIV Testing ([http://data.unaids.org/una-docs/hivtestingpolicy\\_en.pdf](http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf))
3. UNFPA Voluntary Counselling and Testing (VCT) for Prevention. (<http://www.unfpa.org/hiv/prevention/hivprev5d.htm>)
4. UNAIDS/WHO Policy Statement on HIV Testing. ([http://data.unaids.org/una-docs/hivtestingpolicy\\_en.pdf](http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf))
5. Allen in Alcom (2005:5).
6. Alcom (2005), Handsfield (2006), Kalichman & Simbayi (2003).
7. Exner (2002), Handsfield (2006), Kippax (2005), and Thornton (2005).
8. Kalichman & Simbayi, 2003.
9. Kalichman & Simbayi (2003); Alcom (2005); Nieburg et al (2005); Anderson (2006); Kippax (2005).

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# HIV Testing and the Rights of Women Living with HIV<sup>1</sup>

The International Community of Women Living with HIV/AIDS (ICW) observes with alarm the UN's plan to dramatically scale up HIV testing. Not only is there a danger that such a strategy, particularly if tests are opt-out, service provider-initiated, will take the control from women and men to decide and prepare themselves for tests and for results, but there are also many current concerns with testing that have not been addressed and will only be exacerbated with scale-up.

Although we recognise that knowing one's status can sometimes enable us to better protect our health, and that of our partners, we have a number of fears, described below, with planned and current testing practices.

Our main concerns centre around plans to offer service provider-initiated, routine HIV tests, where the emphasis is on the service user to opt-out.

**Limited access to care, treatment and support** – Embarking on routine testing is actually very dangerous considering that there is limited access to care, treatment and support for many women, in many parts of the world, on testing positive. Proponents of routine testing have argued that we cannot scale up treatment access if we don't scale up testing – but let us ensure that quality treatment and care are accessible first! We are diverting scarce resources to the scale up of testing when so many who are already tested, or want testing, need and cannot afford treatment.

Success of testing initiatives is often judged by the number of people tested – quite clearly this is not a measurement of success. Let us not get testing confused with prevention and treatment. The former does not automatically lead to either of the latter, particularly, when treatment is not even available.

**The stigma, discrimination and related violence, and loss of livelihood** that many women face on disclosure are also extremely worrying; a concern that is heightened when women are pushed to test with their partners, or counselled to disclose, before they are ready. In Kenya healthcare staff were horrified when a pregnant woman they encouraged to test was thrown out of her home (told to an ICW member working in Kenya). Such examples from members are all too common. A nod to gender inequalities in literature supporting routine testing is grossly inadequate, given that women make up 50% of people living with HIV and are often targeted for testing through antenatal clinics. Routine testing at health centres may also, inadvertently, have a negative impact on women where they access health services in greater numbers than men, with the consequential blame heaped on her for testing and disclosing first.

Advocates for routine testing say that more testing will normalise HIV. We ask – show us the evidence!

**Pre-test counselling**, and, to a certain degree, **post-test counselling**, are casualties of routine testing and yet, our members

have reported that pre- and post-test counselling are vital in helping them come to terms with a positive diagnosis. Sometimes group counselling has been used to get around the resource constraints of one-on-one counselling, yet, women in South Africa say they feel 'herded' through the process and are less likely to return for results (pers comms: Mags Beksinska, Reproductive Health Research Unit in South Africa).

Outreach testing services that do not offer appropriate counselling and community preparedness can also lead to violent responses by or towards those testing positive (Grace Sedio, ICW staff member from Botswana).

**Informed, voluntary consent will also be lost** – Do people really have the power to opt-out of having a test at health centres, particularly, as healthcare centres are seen by most women as places of powerlessness? Routine testing assumes that somehow, a woman, who may have very limited ability to negotiate, and who has been subjected to subordination all her life, who as a result of her circumstances may have very limited self esteem, is going to meaningfully participate and decide whether she should be tested or not. Literacy and language barriers and a lack of accessible, tailored information, in local languages, makes this possibility even more remote.

**Judgmental, discriminatory attitudes in healthcare settings** – Our members, from the UK, South Africa, Zimbabwe, Thailand and many other countries have repeatedly reported an inability to assert their will in healthcare settings, particularly after testing HIV positive. Rude behaviour on the part of healthcare workers, denial of services and treatments or, indeed coercion regarding certain courses of actions, are common. So

**...we believe that a scale-up of testing will also see a scale-up in stigma, discrimination and criminalisation ... particularly, if public officials interpret widespread knowledge of status to signify wide-spread personal control over transmission...**

what happens to informed, voluntary consent re testing under such conditions? Will women be denied services if they refuse to test, or indeed, if they do test and test positive?

**Confidentiality** – ICW's research shows a worrying lack of concern on the part of healthcare workers for service users' right to confidentiality. Unfortunately another causality of routine testing is likely to be training for health care workers regarding the rights of service users to respectful, confidentiality advice and care.

**Marginalisation and criminalisation** – What happens to sex workers, migrants, drug users and men who have sex with men when they test positive or pregnant women who refuse treatment? In fact, anyone who has limited access to health services and/or is already severely stigmatised and criminalised, could be further disenfranchised and disempowered within a system that enforces HIV testing with limited counselling, care, treatment and support. We believe that a scale-up of testing will also see a scale-up in stigma, discrimination and criminalisation when it comes down to country by country implementation, particularly, if public officials interpret widespread knowledge of status to signify wide-spread personal control over transmission.

**Testing in antenatal clinics** – The current emphasis by the World Health Organisation on testing in ante-natal clinics (ANCs), for statistical purposes and to address mother-to-

child transmission, only serves to reinforce the view that women bring HIV into the family. Disturbingly, the highest reported rates of disclosure-related violence are among women, who test for HIV in the context of antenatal care<sup>2</sup>. Targeting ANCs also shifts the responsibility away from men to get tested. Furthermore, ICW is extremely concerned about the strong focus on testing women (and pressure on women to test) during pregnancy and during birth as pregnancy is an intensely emotional period of a woman's life and finding out, at this time, about a positive HIV diagnosis is extremely traumatic. Preventing mother-to-child transmission is a priority. But we have noticed that the focus of PMTCT programmes is often on healthy babies; the importance of healthy mothers, fathers, and in fact, children (as the babies get older) gets neglected.

Already concerns have been expressed that the small percentage of women accessing ante-natal services, or indeed health services in general, is likely to dwindle if testing is presumed to be mandatory. Moreover, will women return for results or return to get their kids tested if they feel coerced into testing?

Of course HIV testing should be available during this time, but we require more flexibility in the availability of testing facilities, greater respect for our right to choose whether or not to be tested and non-judgmental information and support, so we can make more informed decisions about testing, child bearing and rearing. We support provider-initiated opt-in testing which gives people the right to make personally informed choices.

Another approach is community-wide training workshops that encourage and support community members to go for VCT by, for example, giving members time to address prejudices and fears, their own and those of others in the community. Such an approach could relieve the pressure on pregnant women to test and disclose. ANC testing could then become a fall-back option rather than a first line of action.

**Over all**, we should not be calling for routine, provider-initiated, opt-out testing when 1) gender inequality and HIV-related stigma make disclosure a life threatening prospect; 2) women and men have limited access to care, treatment and support; 3) women and men are not in a position to decide for themselves whether or not they want to be tested; and 4) stigma and discrimination from healthcare providers, in the work place and elsewhere make asserting our rights impossible.

We urge the UN to pay attention to their own guidelines:

*Public health legislation should ensure that HIV testing of individuals should only be performed with the specific, informed consent of the individual.*<sup>3</sup>

**FOOTNOTES:**

1. This is a position paper on HIV testing prepared by the International Community of Women Living with HIV/AIDS (ICW) in June 2006.
2. Maman, S. & Medley, A. 2004. Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, barriers and outcomes: A review paper. Geneva: World Health Organisation.
3. United Nations. 1998. The International Guidelines on HIV/AIDS and Human Rights.

**For comments and/or further information, please contact the International Community of Women Living with HIV/AIDS (ICW) on +44 20 7704 0606 or at [www.icw.org](http://www.icw.org).**



Tshipinare Marumo

# Women: The transmitters of HIV and AIDS

## Gender, HIV and AIDS and Stigma

### INTRODUCTION

The focus of the World AIDS Day campaign for the years 2002 and 2003 has been particularly on stigma, discrimination and human rights. The main objective of the campaign was to prevent, reduce and ultimately eliminate HIV and AIDS related stigma and discrimination, wherever it occurred and in all its forms.

HIV and AIDS related stigma and discrimination are universal, occurring in every country and region. It is triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the pandemics, the fact that AIDS is incurable, social fears about sexuality, and fears relating to illness and death [Aggleton & Parker, 2002:5].

Throughout the world, shame and stigma associated with HIV and AIDS have silenced open discussion, both of its causes and of adequate responses. This has caused people infected with HIV and affected by the disease, to feel guilty and ashamed, to feel unable to express their views, and fearful that they will not be taken seriously. Furthermore, this has led politicians and policy makers in numerous countries to deny that there is a problem, and that urgent action needs to be taken.

The power relations that underscore gender relations and that tightly intersect with discrimination of women mean that women are often not in the position to say 'no' to unwanted and/or unprotected sex. There are well-documented cases of people living with HIV and AIDS who have been stigmatised, discriminated against and denied access to services on the grounds of their HIV status. At work, in education, in healthcare settings and in the

community, people, according to Aggleton and Parker [2002:5], may lack the education to understand that HIV and AIDS cannot be transmitted through everyday contact, and they may also not know that infection can be avoided by the adoption of relatively simple precautions.

HIV and AIDS related stigma is about deep-rooted social fears and anxieties. So, understanding more about these issues, and the norms they reinforce, is essential to be in the position to develop an adequate response to HIV and AIDS related stigma and discrimination. Otherwise, there is the risk of developing programmes and interventions that are not comprehensive, and, thus, achieving very little impact.

### WHAT IS STIGMA?

Stigma is a process of devaluation. The origins of the word '*stigma*' can be traced to classical Greece, where '*outcasts groups*' were branded, or physically marked, as a permanent measure of their status. A stigma is any characteristic that sets an individual or group apart from the majority of the population, with the result that the individual or group is treated with suspicion or hostility [Giddens, 2000:127]. AIDS is an example of illness as stigma, while most forms of illness arouse feelings of sympathy or compassion amongst non-sufferers.

However, when an illness is seen as uncommonly infectious, or is perceived as '*a mark of dishonour*', the '*healthy*' population may reject '*sufferers*'. This was true of people infected with leprosy in the Middle Ages, who were thought to be sinners punished by God, and were, hence, disowned and forced to live in separate leper colonies [Giddens, 2000:127]. In South Africa, the famous Robben Island has been a

place, where leprosy patients were kept away from society. Stigma is not unique to HIV and AIDS only. It has been documented with other infectious diseases, such as TB and syphilis. Stigma is common with diseases that are seen as incurable, disfiguring and severe.

In a less extreme way, HIV and AIDS often provoke such stigmatisation, in spite of the fact that, like leprosy, the danger of contracting the disease in ordinary day-to-day situations is almost non-existent. While a person who is infected with HIV may live for many years without developing AIDS, once the disease is diagnosed, it is effectively perceived as 'a death sentence' [Giddens, 2000:127]. According to Miles [1991:42], whatever meaning is given to health by lay people, ill-health represents a breakdown in the normal, expected state of health and well-being, a situation when things go wrong, a deviation from how things should be, and usually are. Studies of stigma have shown that the stigma associated with HIV is greater, than that of other stigmatised illnesses [Lee, Kochman & Sikkema, 2002:309].

When analysing the roots and results of stigma, it is important to demonstrate how both women and men experience stigma, and are differently affected by it.

## LITERATURE REVIEW

### Gender differences

Different scholars, academics and authors tend to differ on the interpretation of gender differences in relation to both women and men, including the importance of biological versus social and cultural influences on human sexual behaviour. An important similarity in the research on gender differences and on sexuality has been that both fields have looked to the animal world, in an attempt to understand humans.<sup>2</sup> There is a biological basis to sexuality, since female anatomy differs from that of the male. Biologists further argue that there is an evolutionary explanation of why men tend to be more sexually promiscuous than women.

Lorber<sup>3</sup> distinguishes about ten different sexual identities amongst human beings: heterosexual women, heterosexual men, lesbian women, gay men, bisexual women, bisexual men, transvestite

women (women who regularly dress as a man), transvestite men (men who regularly dress as a woman), transsexual men (women who become men) and transsexual women (men who become women).

Due to the fact that sexual practices are diverse, the societal accepted types of sexual behaviour are equally diverse and differ between cultures and societies. However, regardless of the different sexual identities, it is important to note that the values of society in general have traditionally been patriarchal in nature. And because of this, sexism, religion and western attitudes have also tended to perpetuate myths about the differences in gender and sexual behaviour.

Christianity and various different denominations have held divergent views about the role and place of sexuality in society. In the 19th century, religious presumptions about sexuality were partly replaced by medical ones. In Victorian times, there was sexual hypocrisy, in that many men, who were thought of as 'behaved', were the ones who regularly visited sex workers or had mistresses. This behaviour, portrayed by men, was treated leniently, whereas women, who had lovers, were labelled, shunned, branded adulterous and scandalous. The differing attitudes towards the sexual activities of women and men created a double standard, which has long existed and still applies currently.

Religion and the medical and health professions have also allowed sexism, gender and sex stereotypes to influence their practices. Most studies<sup>4</sup> have shown, for instance, that most patients in therapy are women and argue, that the role of patient is highly consistent with a female sex role, characterised by weakness, dependency, irrationality, and acceptance of care.

Relative to the incidence of physical and medical illness amongst women and men, women are more likely to seek medical and psychiatric help. This tendency may be explained in terms of socialisation; a woman's sex role permits her to seek help, whereas men may consider it 'not masculine' to do so.<sup>5</sup>

Modern feminist psychologists<sup>6</sup> have pointed out several socio-cultural factors, rather than inferior biology, as contributing to the denigration of women.

Images of women throughout history have been fearful or unflattering. In some cases, women were portrayed as seductress, lustful, evil, needing to be controlled, subordinated and devalued. Women were, and are still, treated as property, burned, raped and accused of being witches and excluded from positions of power. All these factors perpetuate and justify men's need to control women.

### HIV and AIDS related stigma

A survey, conducted in 2002 amongst some 1,000 physicians, nurses and midwives in four Nigerian states, showed rather disturbing findings. One in ten doctors and nurses admitted to refusing care for a patient with HIV and/or AIDS, or to denying patients with HIV and AIDS admission to a hospital. Almost 40% thought a person's appearance portrayed her or his HIV positive status, and 20% felt that people living with HIV and AIDS had behaved immorally and deserved their fate.

A lack of knowledge about the HI virus, often combined with denigrating attitudes towards people living with HIV, seemed to be one factor fuelling stigma and discrimination. Another factor highlighted was the fear amongst doctors and nurses about exposure to possible infection, as a result of lack of protective equipment. Also, at play, it appears, was the frustration about the lack of medicines for treating patients infected with HIV and AIDS, who, therefore, were seen as '*doomed to die*'.

Studies in other regions show that such attitudes and actions seem to be common. In the Philippines, a recent study amongst people living with HIV and AIDS found that almost 50% of respondents had experienced discrimination at the hands of healthcare workers, while in Thailand, 11% of respondents said they had been denied medicine, because of their HIV positive status, and 9% had experienced delays in treatment.

In a research study in India, some 70% of people living with HIV and AIDS said they had faced discrimination, most commonly within families and in healthcare settings. Such experiences have prompted efforts to promote the greater involvement of people living with HIV and AIDS in India, where several NGO's and networks of people living with HIV

and AIDS are working together to reduce discrimination in local hospitals.

Many people living with HIV and AIDS do not get to choose how, when and to whom to disclose their HIV status. When surveyed recently, 29% of persons living with HIV and AIDS in India, 38% in Indonesia, and over 40% in Thailand said their HIV positive status had been revealed to someone else, without their consent. In many cases, test results were shared with persons other than the spouse or family members; one in nine respondents in a Thai survey said that their HIV positive status had been disclosed to government officials.

These kinds of violations of the right to privacy also undermine HIV and AIDS programmes by deterring people from finding out their HIV status and, thus, threaten public health, as individuals unknowingly transmit HIV. Given the close links between HIV and AIDS related stigma, discrimination and human rights violations, multiple intervention programmes are needed.

Stigma devalues and discredits people, generating shame and insecurity. Stigma is harmful both in itself, since it can lead to feelings of shame, guilt and isolation of people living with HIV, and because it prompts people to act in ways that directly harm others and deny the access to services and entitlements. Such unjust treatment is tantamount to a violation of human rights.

People living with HIV and AIDS have been stigmatised and discriminated against worldwide since the epidemic began. In South Africa, incidences of overt discrimination, including violence, remain common.

In South Africa, up to 37% of rural women attending antenatal clinics test positive for HIV in annual anonymous surveillance surveys<sup>7</sup>. According to Wassenar & Richter [2000:6], women are often seen to be the axle around which HIV infection in Southern Africa revolves. While men, primarily through sexual intercourse, infect women, women infect their infants, through pregnancy, childbirth and breastfeeding.

HIV and AIDS are today seen as the most serious pandemics and threat to public health systems around the world. Since its discovery in the 1980's, the number of infections has increased every year. In

South Africa, by the year 2000 an estimated 5 million South Africans were infected with HIV and AIDS. It has also been estimated that more than 60 million people worldwide have lived with HIV and AIDS since its genesis, and 20 million people have, as a result, since died.<sup>8</sup> On 29 January 2004 at 12:40 pm, worldwide HIV infections were estimated to be 55 769 791 at 12:40 pm<sup>9</sup>.

HIV and AIDS remains a highly stigmatised disease amongst African communities and other communities worldwide. Stigmatisation is currently the biggest obstacle to responding to the pandemic. There is also the challenge of addressing the stigmatisation of condoms. Many people living with HIV and AIDS experience discrimination from strangers, families, friends, lovers, healthcare workers and government. Discrimination is a result of ignorance [HIV in our lives, 2003:67]. Many people still do not know how HIV is transmitted, and lack of knowledge often leads to fear about HIV.

Stigma has been studied by relatively few social scientists. According to Levett [1995:4], stigma is not a simple matter of labelling, or being labelled, although it includes these; inequality and difference are always implicated. Lee & Loveridge [1987:1] argue that inequality

*...is a social construct supported by a complex process in which characteristics are attributed to the disadvantaged which then become the justification for that disadvantaged position in society. This stigmatization in turn further handicaps any attempts by the disadvantaged to alter or challenge this apparently normal set of hierarchical social relationships.*

Perceptions that have come out from traditional rural communities have been that condoms are a western product and not African and, therefore, a carrier of HIV and AIDS. Furthermore, stigmatisation has been, and continues to remain, the main obstacle for people wanting to disclose their HIV status. For example, in Botswana, treatment for people living with HIV and AIDS is accessible, but yet, people are not coming forward, because of the way society treats people when their HIV positive status becomes known.

At the XIV International AIDS Conference,

Nelson Mandela stated that '*stigma, discrimination and ostracism are the real killers*'. In his closing speech, he added that '*AIDS is a war against humanity*'.

## AIM OF THE STUDY

South Africa has one of the world's highest HIV infection rates, but people seem to deny the disease, because HIV is linked to sex. People living with HIV and AIDS, are seemingly labelled, in South Africa and globally, as living an '*immoral life*'. It also appears that discourses on HIV and AIDS intersect powerfully with social taboos and stigmas related to sexuality and gender.

Over the years, women have tended to be labelled or branded as the '*transmitters*' of the HIV and AIDS disease. A number of studies have focused on women and HIV and AIDS, however, most of these studies have focused more on women's greater vulnerability to the HIV and AIDS pandemics.

The purpose of this study is to investigate the way in which gender identity intersects with constructions of HIV and AIDS, in particular to:

- investigate whether or not HIV and AIDS is seen as a woman's disease and why;
- investigate if and why women are more stigmatised than men;
- determine what socio-economic and cultural issues contribute to the stigmatisation of women living with HIV and AIDS;
- document community responses to, and perceptions of, HIV and AIDS, in particular stigma, attached to both women and men living with HIV and AIDS.

## METHODOLOGY OF THE STUDY

The study utilised qualitative research methods. The data was collected through six focus group discussions, and provides a narrative analysis of focus group discussions. Socialist feminist research methodology also guided both the research methodology and the focus group discussion, so as to encourage debates on gender and sexuality.

Socialist feminists view patriarchy and capitalism as equally important forces in explaining the inequalities in society. Socialist feminists study how



differences amongst men, in the access to power and other resources, help to explain the different ways in which men exploit women; and focus on the social relations of power, especially economic power, that enable men to control women. It is for this reason that this method was adopted so as to provide an understanding of the social implications of HIV for women and men, and not to examine the issue in isolation from the position of both sexes, economically and otherwise.

A vignette was used in the focus groups to introduce the topic to the participants. The vignette showed a protruding hand of a man pushing a critically ill woman away. The use of the vignette was to gauge people's perceptions about HIV and AIDS related stigma.

## THE DATA COLLECTION PROCESS

The target population of this study was the focus groups that included both women and men, between the ages of 18 and 55 years, living within the vicinity of the Khayelitsha Township in the Western Cape. Each group included between 10 – 12 participants. Some groups were mixed and some had same-sex group members. Most of the participants were unemployed and some came from the different sections of Khayelitsha.

The fieldwork commenced in July 2004. The purpose of the fieldwork was to record community perceptions and responses to HIV and AIDS and stigma. A total of 62 community members participated in the six focus group discussions facilitated in Khayelitsha, Western Cape.

## MAJOR FINDINGS

The data illustrated the problems that women, living with HIV and AIDS, face on a day-to-day basis. In all the focus groups, participants shared their different reactions, experiences and perceptions of HIV and AIDS, as well as of HIV and AIDS related stigma.

Experiences, reactions and perceptions of the participants include:<sup>10</sup>

- Much of the stigma attached to HIV and AIDS is the belief that women infected with HIV got infected due to their promiscuous behaviour – *'If we see a HIV positive women, we normally put it*

*to be that she behaved immorally and that she has been promiscuous'.*

- Unemployment, 'sugar daddies', and socio-economic factors are the reasons why women are more vulnerable to contracting HIV – *'The sugar daddies, unemployment and socio-economic factors contribute to the acceleration of HIV/AIDS'.*
- Young girls are encouraged to have unprotected sex with older men, who have material possessions, such as money and an expensive car – this is based on the concepts of 'izibethi', 'ingangara', 'indoda', or 'o fuze Tata wakhe', meaning 'he is like his father' or 'like father like son', which particularly tends to mislead the youth and the elders in that a man, who has many girlfriends, is seen as a 'boss', and perceived to portray some kind of 'township masculinity'. While the combination of money and an expensive car tends to place people at a high risk of HIV infection, men's promiscuous behaviour, dominance and economic advantage encourage and perpetuate patriarchy, leading to the pervasive spread of HIV and AIDS.
- Sex has become a commodity, in that women who have no money tend to get a man, who will assist financially and bring groceries to the house – *'Women normally think about kids, the family welfare, and as a result for them to have to put bread or food on the table, they end up doing services or sleeping with other men, just to make sure that she keeps the home fires burning'.*
- Young girls are particularly at high risk of HIV infection – *'They (young girls) are after money, clothes, fashion'.*
- People who live with HIV are subjected to gossip and ridicule – *'They are seen as a curse, a shame and as carriers of the disease'.*
- Family members are not honest about their feelings towards people living with HIV and AIDS – *'Stigma also starts at home, for example, you won't wash dishes or at times you won't be told directly that you should not do this or that'.*
- Men are given comforting names, such as 'izibethi' and 'indoda', whilst women are given denigrating names, such as 'Hoover', 'isifebe', and 'henyukazi' – *'They (women) are called isifebe*

(bitch) or Hoover, like a hooving machine, because a Hoover take all the dust and everything it comes across’.

- Churches and religious bodies fuel stigma – ‘They’ll tell you that HIV/AIDS doesn’t exist’.
- Women are part of stigmatising other women, which further fuels stigma – ‘Stigma is also fuelled by women themselves’.
- HIV testing and disclosure is recognised as difficult, because of stigma, violence, loss of income, blaming and being condemned – ‘People who are HIV positive are not seen as humans, the person is seen as an animal; he or she cannot live within the community. Rather the person can go and stay alone somewhere else’.
- Traditional healers fuel stigma – ‘Traditional healers point fingers, if they can’t diagnose your condition, they’ll say you are bewitched by so and so’.
- Male power and promiscuity is endorsed by the community and males are often protected – ‘Men are called names like ‘players’ and these names are the ones that promote promiscuity amongst men, because ‘you are a boss’.
- Men who have money or income are at greater risk, than men who do not have any income – This is evident in the construction of ‘izibethi’ or ‘ingangara’, who have money and material possessions, and multiple girlfriends or partners.
- The effect of HIV related stigma is experienced differently for women and men – ‘If a man is HIV positive, he will not be stigmatised or called degrading names, in the way as a woman’.
- Clinics, health institutions and nurses aggravate and perpetuate stigma – ‘Nurses and counsellors should not sit in offices or clinics, they must also go to the community, because the stigma also comes from nurses as well. They gossip about patients and it becomes worse when this reaches the community’. Or, as another participant stated: ‘When you enter the clinic, you’ll find that nurses like to be in groups gossiping. This gossiping contributes to the stigmatisation of people’.
- Males are seldom stigmatised – ‘Because men

have power or physical power, this serves as a threat to those who want to stigmatise men’.

- Women, who become infected with HIV, are often seen as sex workers – ‘Prostitutes are the ones, who are spreading the virus’.
- Women, who do not breastfeed, are believed to have tested positive for HIV – ‘When I had my first child, I didn’t breastfeed her and the second wasn’t breastfed, whilst the third was breastfed. All because these children did not want to be breastfed anymore – so it ended up like people become suspicious, that you are HIV positive’.
- Images of HIV and AIDS in the media tend to suggest that it is ‘a gay disease’, ‘an American disease to wipe out Africans’, and ‘a woman’s disease’ – these stereotypes fuel stigma and reinforce cultural beliefs.
- Most women die of HIV and AIDS, so it is ‘a woman’s disease’ – ‘Women are to blame, because it is mostly women who die from HIV/AIDS’.
- Men refuse to wear condoms – ‘I can’t wear a raincoat – some men would say that they haven’t seen their grandfathers and parents wearing a raincoat and they won’t do it as well’.
- Impact of stigma is mediated by gender and its impact is experienced more by women – ‘Women look after children, they are home managers and they are weak biologically’.
- For many women, who are infected with, or affected by, HIV and AIDS, their position is characterised by financial dependency and, thus, their financial or social position cannot be examined in isolation from their position in society.
- Culture, as a belief and practice of a community, serves as a design for living, is transferred from one generation to the next, and is normally slow to change. As a result ‘men don’t want to use condoms, culture dictates that. If I, as the wife, request the use of a condom, he will call the elders’. Others will say that ‘o galela plastiking’, meaning ‘you are ejaculating into a plastic’.
- People living with HIV and AIDS are subjected to gossip, ridicule, and rejection. Many women are also subjected to violence, once their partners know their HIV status.

## CONCLUSIONS AND RECOMMENDATIONS<sup>11</sup>

This study focused particularly on one South African township, Khayelitsha. It would be important to have comparative studies in other South African townships to find out, whether or not people hold similar beliefs and whether or not there are similarities with what has been highlighted in Khayelitsha.

This study revealed that women, due to their social or economic status, place, at times, their health at risk. Women, who are in marriage, cannot negotiate safer sex, and the same applies to women who are unemployed, due to *'buying power'* that working men have, and men, who have *'buying power'*, tend to target women, who are economically vulnerable and responsible for their family's welfare.

Women are much blamed for their HIV infections and, as a result of the stigma attached to HIV and AIDS, women face different experiences, frustrations, and negative responses.

Culture tends to oppress women, since *'according to culture men are the ones, who have power and control'* [participant].

Some of the recommendations from participants included:

- Health workers should be educated on how to educate the public around HIV and AIDS, since they do not have a good approach to patients and people.
- Support groups should go into the community. They should have road shows and drama groups. *'It is important to have respected persons from the stigmatised community to share their life stories'*.
- People living with HIV and AIDS should form part of community projects, since *'they should be seen as productive people'*.
- There should be posters, *'as big as ANC posters depicting President Thabo Mbeki'*, and posters should be visible and should not only be in the clinic.
- Parents should talk about HIV and AIDS to their children, *'though it is difficult to discuss sex with kids'*.
- We must change the strategy in HIV and AIDS education; explain whether or not HIV causes

AIDS, since *'this has still not been explained to ordinary people'*, and get celebrities, who are infected with HIV, to be part of the awareness programmes.

- Families and parents should be a platform where the issues of HIV and AIDS are raised to further reduce stigma.
- There should be a law enacted to deal with stigma and the law should be harsh and have a punishable offence; this could deter people from accusing and labelling each other; *'the solution for stigma is to arrest the perpetrators'*.
- More and more community workshops are needed.
- Put more messages about HIV and AIDS stigma on television, in programmes like *'Asikhulume/Let's talk'*, and on radio to further educate people about stigma. *'We should intensify public awareness and education campaigns'*.
- The Department of Health needs to be on board and the department should print T-shirts and tracksuits.
- Government should do something about the clinics and clinic staff; most are not working.
- Treatment information should be shown on posters.
- We must challenge stigmatising statements, such as *'People who sleep around deserve what they get'* or *'If I got HIV/AIDS, I'll kill myself'*.

## LEARNING OUTCOMES

While the participants in these focus groups were not asked their HIV status, one could pick up that there were participants who feared stigmatisation from their respective communities.

As mentioned above, it would be important to examine the underlying meaning of words, such as *'hoover'*, *'ingangara'*, and *'izibethi'*, because there might be different variations of these concepts in the different townships and rural areas of South Africa. But most importantly, it seems that the concepts of masculinity and femininity needs to be redefined, especially in the face of the HIV and AIDS pandemics.

There is also still a need to come up with new programmes to de-stigmatise HIV and AIDS. People tend to think of HIV and AIDS as *'destructive'* and

representing some form of 'inactivity' and exclusion from society. Throughout the focus group discussions, it became obvious that people also tend to rely on the sum of knowledge and beliefs that exist in the community, place and society, without necessarily questioning it. So, here it seems to become important to use indigenous knowledge systems as a tool to educate people, since oral tradition tends to be an important aspect for the African community.

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## FOOTNOTES:

1. This article is based on a research paper, which formed part of doctoral studies in Women & Gender Studies at the University of the Western Cape. The research, conducted in 2004, has been supervised by Professor Tammy Shefer, Department of Women and Gender Studies, University of the Western Cape.
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5. Chesler, 1971; Shapiro et al, 1984, as quoted in Sue, Sue & Sue, 1994. supra note 3.
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9. Mail & Guardian HIV Barometer, January 30 – February 5 2004.
10. The quotes are statements from participants in the various focus group discussions, based on the transcripts of the sessions.
11. The quotes are statements from participants in the various focus group discussions, based on the transcripts of the sessions.

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Busari Olusegun

# Between Patients' Rights and Doctors' Safety: Forced HIV Testing of Patients in Nigeria

## Background of the Nigeria state

Africa has become the habitat for HIV and AIDS with about 28 million people living with the virus. Nigeria, the most populous black and African nation, has a good proportion of people living with HIV and AIDS. Nigeria is a country that is yet to come out of the socio-economic and political coma precipitated by decades of military misrule, monumental corruption and looting of public treasuries.

During these painful past years, Nigeria and Nigerians were impoverished, societal values and ideas were broken, the infrastructure collapsed and family and community ties severed, due to increasing proportions of people living in extreme poverty. The military fractured the Nigerian society and militarised people's psyche and mentality. Little wonder, an average Nigerian is hungry and angry, works under pressure and exhibits a 'force mentality'. Medical doctors and other health workers are no exceptions. Many Nigerian doctors have migrated to the West for greener pastures, and the remnants at home are barely surviving, working under terrible work conditions of poor wages, dilapidated health infrastructure and an empty consulting room.

Most hospitals lack structures that protect doctors and other health professionals from workplace injuries and death. Government and hospital administrators border less on the welfare and safety of doctors and their right to protection, even at health institutions. The anti-human right posture of the military has permeated the fabrics of the society such that the culture now is; once one has more might or more privilege, one can override the next person next and abuse his or her rights. Government and health institution administrators override doctors and doctors visit their frustrations on patients, and the cycle of abuse continues.

## HIV and AIDS and Militarization

The evolution of HIV and AIDS in the 1980s, and its

destructive ascension over the last two decades, has further impoverished the Nigerian state and its people. HIV and AIDS burst the remaining few bubbles of hope left by the military. It has put a lot of burden on the collapsed health infrastructure, redefines health needs and priorities of communities, and overstrains the scarce human and material resources in the health sector.

## Doctors' safety is in question

Doctors have 'battalions' of patients to attend to and are exposed to greater and harsher workplace hazards, as more and more people are infected with HIV and accessing care. Yet, doctors are not protected by any serious hazard protection policies or systems, or health insurance.

In Nigeria, HIV and AIDS poses the biggest hazard risk to doctors and other professionals working in health institutions. Things are so bad that there may not be water to clean up one's hands after attending to patients on the wards. Routinely used simple materials and consumables such as gloves, methylated spirit, masks, etc, are not available in many hospitals in the country. If a doctor has an accidental needle injury, nothing can be done, since Post-Exposure Prophylaxis (PEP) services are a luxury in most health institutions. Generally speaking, they do

not exist. There is no insurance cover. A doctor's hazard allowance per month is less than 100 USD.

So, what we have in Nigeria are poor, frustrated and endangered doctors who pass their anger and frustrations on to their patients and clients. Nigerian doctors are well educated, but lack general knowledge of human rights. Doctors do not even know that they themselves have rights, including the right to work in a safe environment, to be protected from hazards and to be cared for in cases of accidental injuries. Not surprisingly then, that doctors brazenly abuse patients' rights and impose HIV testing on patients, without consent and often even without their knowledge.

### **Involuntary and/or forced HIV testing**

What we have in many health institutions in Nigeria is either involuntary and/or forced HIV testing. Voluntary counselling and testing only exists in the realm of policy and/or theory. In many instances, patients are not informed at all about the testing. No pre-test counselling, no information, no consent sought – the doctor only collects the blood sample, labels it with a code name and the patient pays for the test. To add insult to injury, patients, whose results come out HIV positive, are left alone. I use the word 'alone', because it best describes what happens in most instances. Even, when post-test counselling is done, it is usually shallow, inconsistent and ineffective. This is not only unethical, but also an abuse of patients' freedom to make an informed choice on issues of health and life, and an obstruction of access to information.

The 1999 Constitution of the Federal Republic of Nigeria states categorically that

*...every Nigerian citizen, child or adult, male or female, irrespective of culture, language, religion, section or region, has a right to health, life and access to good health services.*

The bitterest part of this injustice is the issue of forced HIV testing. This is a little bit different from what I have discussed above, which I call 'involuntary testing'. In forced testing, patients are given the option to leave the hospital, or seek the service of another doctor, if they would not agree to be tested for HIV.

### **Recommendations**

There is need for an awareness campaign among doctors and other health professionals to be educated on the right of the patients to make an informed decision on whether or not to know their HIV serostatus. There also needs to be education on the medico-legal implications of health services.

In addition, all doctors must have a proficiency in basic HIV counselling skills and all health institutions must have professional HIV and AIDS counsellors and HIV and AIDS social workers.

On a general note, the Nigerian government and policy stakeholders should improve the welfare and workplace safety of people working in the health sector.

And finally, HIV and AIDS rights activism in Nigeria must be scaled up to respond to all these gross violations of rights in the context of HIV and AIDS.

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making a point

Lukas Muntingh and Christopher Mbazira

# Prisoners' access to anti-retroviral treatment<sup>1</sup>

*Case review of EN and others v The Government of South Africa and others* (Durban High Court, Case No. 4576/2006) [unreported] (*EN and others case*)

Prisoners are susceptible to a number of illnesses and diseases. This may relate to the conditions of prisons themselves (e.g. poor ventilation is associated with TB), life style (e.g. poor nutrition and substance abuse), and sexual violence (e.g. male rape in prison). From a healthcare perspective, prisons present a particular challenge. From 1996 to 2005, the number of prisoners dying from natural causes per year increased from 211 to 1507. HIV and AIDS have contributed to this increase.

The rate of HIV infections amongst prisoners is unknown and the Department of Correctional Services (the Department) has commissioned a research project to establish this. In the absence of accurate and publicly accessible data, it is difficult to make any accurate assessment of the size and scope of HIV infection and persons living with AIDS in our prisons. What we do know is that prisoners' access to anti-retroviral treatment (ARV) is extremely limited. To date, only one accredited ARV treatment centre has been established by the Department at Grootvlei Correctional Centre in the Free State.

In September 2005, the Department briefed the Parliamentary Portfolio Committee on Correctional Services regarding prisoners' access to ARV with reference to the '*HIV/AIDS Policy for Offenders*'. It reported that the Department was

not accredited to provide ARV to prisoners. It also noted that the ARV roll-out centres were located off-site at the Department of Health facilities, which created security concerns as a result of lack of staff and logistics (e.g. transport).

In essence, the Department position was that, while it would like to provide access to ARV, it lacked the resources (staff and infrastructure) to do so. The applicants in the present case sought to remove all obstacles preventing the prisoners from accessing ARV.

## FACTS

The AIDS Law Project (ALP) assisted 15 HIV positive prisoners (the applicants), serving sentences at the Westville Correctional Centre (WCC), to bring an application to the Court:

- to compel the government to remove all obstacles preventing them (and other qualifying prisoners) from accessing ARVs at accredited public healthcare facilities;
- to seek an order that they be provided with ARV in respect of the established government Operational Plan for Comprehensive HIV and AIDS Care (the Operational Plan);
- to require it to issue a structural interdict compelling the government to report to it within one week on the measures they will take to give effect to the relief granted.

The application was preceded by a fairly lengthy but largely unproductive process of meetings and correspondence between the ALP and the WCC and the Head Office of the Department of Correctional Services. This process began in October 2005 and by March 2006 the ALP came to the conclusion that it would bear no fruit. It launched the application in the Durban High Court on 12 April 2006.

The respondents were the Government of the Republic of South Africa, Head of Westville Correctional Centre, Minister of Correctional Services, Area Commissioner of Correctional Services (KZN), Minister of Health and MEC for Health (KZN). They apparently attempted to undermine the application by contesting some technical matters, such as the locus standi of the applicants, the urgency of the application, and the validity of the founding papers. Justice Pillay dismissed these arguments.

### ARGUMENTS

The applicants' arguments were simple and straightforward. They argued that the respondents had failed to meet two constitutional obligations in respect of the right to health in Sections 27(1)(a) and 35(2) of the Constitution<sup>2</sup>. Section 27(1)(a) guarantees everyone the right of access to healthcare services, which the state must realise progressively subject to available resources. Section 35(2) guarantees to every detained person the right to conditions of detention, which are consistent with human dignity, including medical treatment.

The applicants argued that the Operational Plan had not been implemented reasonably owing to the lack of speed. All they sought was an order, compelling the respondents to fast track implementation of the Operational Plan to enable

that the applicants, and similarly situated prisoners, be assessed for ARV treatment.

As is often the case in socio-economic rights litigation, the respondents attempted to seek refuge in the doctrine of separation of powers. They argued that the applicants were asking the Court 'to prescribe ARV', a task falling beyond the Court's competence.

The respondents, while not contesting the principle that a court can grant a structural interdict, argued that it was not necessary in this case, because they were implementing the Operational Plan. They also argued that the issuance of structural interdicts in certain circumstances may amount to unwarranted interference with the authority and discretion of the executive arm of government in violation of the doctrine of separation of powers.

The respondents also argued that the applicants were already being taken care of under what was described as a Wellness Programme. The applicants contested this assertion and no evidence was led by the respondents to substantiate their claim.

### THE DECISION

Judge Pillay dismissed the respondents' arguments. He focused on the urgency 'to remove all obstacles preventing the applicants (and other qualifying prisoners) from accessing ARV at an accredited public health facility'. He stated that what was being sought was the removal of unnecessary delays in the treatment of the prisoners, as this was indeed a 'matter of life and death'.

According to the Judge, the question in the case was whether or not the respondents were meeting their constitutional obligations by taking



reasonable steps or measures to ensure that the applicants were receiving adequate medical treatment. There was no argument on the part of the respondents that they were constrained by resources in their endeavours to ensure adequate medical treatment for the applicants.

The judgment describes in detail the history of the case and the apparent lack of seriousness on the part of the respondents in dealing with the applicants' problem:

*The dilatoriness and lack of commitment by the respondents as evidenced by the correspondence forming part of the founding affidavit is quite evident. It seems to me that but for the intervention of the State Attorney, who used his good offices to convene the round table meeting which took place on the 15th of December 2005, the ALP may well have had good cause to have launched this application earlier.*

The Judge castigated the respondents for their inflexibility, as exhibited in their argument that they were bound by the Operational Plan and its guidelines, which they were implementing. It was apparent to the Judge that the respondents were implementing the Operational Plan without due regard to the circumstances of prisoners, yet the plan itself had room for flexibility.

Relying on the precedent in *Government of the Republic of South Africa and Others v Grootboom and Others* 2001 (1) SA 46 (CC) the Court held that the respondent's implementation of the relevant laws and policies in this case was unreasonable as it was inflexible, characterised by unexplained and unjustified delays and irrationality.

## THE ORDER

The Court granted the relief sought by ordering the respondents, with immediate effect, to

remove the restrictions that prevent the applicants and similarly situated prisoners from accessing ARVs. An order was also issued that ARVs be provided to the applicants and similarly situated prisoners in accordance with the Operational Plan.

The Court made a structural interdict granting the relief sought (for example, the removal of obstacles) and ordered the respondents to submit to the Court by 7 July 2006 (two weeks after judgment) a plan as to how they intend to comply with the orders above. While acknowledging the sensitivity of a structural interdict, the Judge held that the case was one in which such an order was required. Nothing rational or workable had been done by the respondents for the applicants and similarly situated prisoners.

## CONCLUDING OBSERVATIONS

This case reinforces the jurisprudence of socio-economic rights in the South African Constitution. It also affirms the longstanding principle that the rights of prisoners that can be limited are only those that are necessary for a sentence of the court to be administered. Prisoners retain all other rights.

The judgment gave a pronounced expression of the right of access to healthcare and the duty of the state to provide such access. The state has the primary responsibility to provide access to healthcare, because these prisoners are placed in the care of the state and do not have the means or ability to access medical care on their own. A prisoner cannot approach a different hospital or arrange for his own transport – he or she is dependent on the state to provide this. This absolute dependency places prisoners in an extremely vulnerable situation. The duty of the state towards prisoners is, therefore, inescapable.

Interestingly, the respondents did not raise the issue of resources as was the case when the Department briefed the Portfolio Committee on Correctional Services in September 2005. This may have been done for two reasons. The first is that the 'resources argument' is not a convincing one in some cases, and the Constitutional Court has already made this clear. The second is that the respondents believed that they were indeed meeting their constitutional obligations.

However, the key question here was whether or not they were taking **reasonable** steps or measures to ensure that the prisoners were receiving adequate medical care. The evidence showed that they were not. An arrangement for the treatment of prisoners was made with only one out of a possible seven hospitals and this hospital agreed to see four prisoners per week. This arrangement was regarded as inadequate, as it would have taken more than 3 weeks to assess the applicants and more than a year to assess other similarly affected prisoners at WCC. It was, therefore, clearly not possible under this arrangement for qualifying prisoners to receive their weekly treatment.

The judgment also reflects on the fact that prisoners did not receive any special mention or attention in the Operational Plan and Guidelines. This was regarded as a shortcoming and probably one that could have been foreseen, given the high number of prison deaths.

The structural interdict granted should be regarded as the result of the poor track record of the respondents in this case. Their lack of cooperation, tardiness and general unwillingness to show good faith in assisting with the applicants' problem created a situation where it would have bordered on irresponsibility on the part of the Court to have done otherwise. The

willingness of the Court to intervene in this manner is seen as a positive development when vulnerable persons find themselves in need of protection. In this case, the state was compelled to deliver in a real and tangible manner on the right to adequate healthcare.

The judgment also recognises that it is indeed a matter of life and death and requires urgent action. It stated *'that the graver the threat to fundamental rights, the greater the responsibility on the duty bearer'*. Binding the respondents to a time frame in this case helped to underscore the significance of the violations at hand.

This judgment means that all qualifying prisoners are entitled to be given access to ARVs. Unfortunately, however, the victory has been short-lived. The respondents have filed an appeal against the judgment. It is seeking leave to appeal to a full bench of the provincial division of the KwaZulu-Natal High Court. Sadly, this means that the successful applicants will have to wait until the legal battle is over before knowing whether or not they are entitled to ARVs.

### **UPDATE ON *EN AND OTHERS V THE GOVERNMENT OF SOUTH AFRICA AND OTHERS*<sup>3</sup>**

On 25 July 2006, Judge Thumba Pillay ordered the government to comply with his earlier judgment regarding access to ARV treatment at Westville Correctional Centre (WCC). Due to the fact that the government applied for leave to appeal against that judgment, the execution of Judge Pillay's order was suspended until the final determination of the appeal.

On 20 July 2006, the lawyers for the prisoners argued that it would be unacceptable to allow the order to remain suspended until the appeal is finalised, as this may take a year or even longer.

During this time the health of the 13 prisoners (and others at WCC who are in a similar position) would decline even further, and some may die. There is no doubt that the urgency here is one of life and death.

On 25 July 2006 Judge Pillay stated:

*One cannot, on the one hand, hail the values of our Constitution which holds the right to life as sacrosanct and on the other, allow people to die in a situation when something can and should be done, certainly more diligently, to counter a pandemic which has been described as an 'incomprehensible calamity' and the 'most important challenge facing South Africa since the birth of our new democracy.'*

The Judge also noted that on the government's own version, nine prisoners per month have died since 2005 of AIDS-related illnesses. This figure in itself demonstrates the urgency of the matter. If the government were complying with their constitutional obligations, as they say they are, why would there be this alarming AIDS-related death rate?

As a result, the Judge ordered that the 22 June 2006 judgment be implemented forthwith, and that the government's report (on the steps that they are taking to ensure access to ARV treatment at WCC) must be filed with the Court by 14 August 2006.

He also granted the government leave to appeal to the full bench of the Natal Provincial Division. Despite the fact that his order will be executed in the interim, he recommended that an expedited date should be allowed for the appeal hearing.

**FOOTNOTES:**

1. This article first appeared in ESR Review, Vol 7 No. 2, July 2006. It is reproduced here with full acknowledgment and appreciation to ESR Review.
2. The Constitution of South Africa, Act 108 of 1996.
3. This update is based on a press statement issued by the AIDS Law Project on 25 July 2006.

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# Say No! To Criminalising HIV Transmission

For more than 20 years, those most involved in the fight against AIDS, including people living with the virus, fought against the ostracisation and discrimination of people living with HIV. For more than 20 years these same people continue to exhaust themselves so that the rights of people living with HIV are not trampled on. It took more than 20 years for certain modest laws to be drafted to protect people living with HIV; more than 20 years for people not to be seen by some as 'plague-carriers'.

But, it only took one or two years in an atmosphere of complete ignorance and indifference – and this includes numerous organisations and institutions – for repressive laws to be approved, more and more each day, that criminalise the transmission of HIV and turn people living with the virus into public health dangers. They will no longer be persons living with a virus, but purely vectors of transmission, potential contaminators!

From now on, in a world where someone has to take the blame for society's ills and life's ups and downs, where the law will meddle in our lives on the most intimate level, people living with HIV become the target of choice. Just when some are announcing the banality of HIV, that discrimination has become less frequent, just when governments nationally and internationally are congratulating themselves on the progress made in the fight against AIDS, people living with HIV are being attacked in courts of law for not having told their partners that they may have engaged in 'risky practices' in the past. Today, people living with HIV are ordered to list their past and future partners. There are those who believe that the specter of jail is a new prevention tool, bringing absurd hope that criminalisation will push back the epidemic, while it in fact creates fertile ground for it to thrive.

Will we soon be seeing children taking their parents to court because they were infected while they were in their mother's womb, during birth or by their mother's milk? Soon, people living with HIV will have to stop having sex! Even protected sex! Even freely consenting partners will stop having sex for fear that the condom might break, for fear that they will infect their lovers, despite precautions they took together, and for fear that the relationship will end in a court case. People living with HIV will soon have to go underground again.

It is time, once again, to remind the world that being infected with HIV does not mean becoming a danger to public health. In the North, as in the South, regardless of the cultures, traditions and societies in which we live, to threaten persons living with HIV with prison, compelling them to be afraid of their sexuality, forcing them to reveal their HIV status in a way that is humiliating – in order to travel, to qualify for insurance, to get married, to have children or to participate in an international conference – is decidedly unjust.

Despite the reality of scientific progress and the advances made in care and treatment, despite the support of people who care, families and nations, it is now very difficult to live with HIV. The right to live a normal life goes hand and hand with enduring support, renewed solidarity, permanent respect, and certainly not through humiliation, rejection and fear.

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