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Scaling up HIV testing: human rights and hidden costs

The calls for provider-initiated routine HIV testing are growing more intense. In this article, Joanne Csete and Richard Elliott discuss the human rights and ethical issues raised by the routine testing approach. Some points in this paper are inspired by an international expert meeting on HIV testing and human rights convened by the Center for Health and Gender Equity, Gay Men's Health Crisis and the Canadian HIV/AIDS Legal Network in Montreal in October 2005. The meeting was attended by academic experts, UN officials, activists and people living with HIV/AIDS from around the world.

The World Health Organization (WHO) estimates that only about 10 percent of persons living with HIV/AIDS in low- and middle-income countries know their HIV status;¹ this is a global crisis. Access to humane and accurate HIV testing is essential for an effective global response to HIV/AIDS. There is complete consensus among AIDS activists and policy-makers in favour of universal access to affordable and high-quality HIV testing. There are differing views, however, on the essential elements of HIV testing and on the means by which universal access to HIV testing should be achieved.

The objective of this article is to respond to the increasingly frequent and forceful calls to accelerate the expansion of HIV testing by redesigning accepted international norms of HIV testing. In the proposed new approach, sometimes described as "routine testing," HIV testing would be initiated by test providers rather than by those tested and would not necessarily include counselling about HIV/AIDS, the

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opportunity for the person tested to consent to the test in an informed way, or a guarantee of confidentiality of test results.

The ground shifts

In the early years of the HIV/AIDS epidemic, there were aggressive calls for punitive or forcible testing for this new and feared disease. These were sometimes accompanied by calls to ensure that the HIV status of those who tested positive for HIV should be publicly known – in the worst cases, that these people be known in their workplaces and communities as HIV-positive, even that they be tattooed to show their status.

AIDS activists understood that those most affected by the disease, particularly gay and bisexual men and drug users, were already socially marginalized, stigmatized, in many cases even criminalized, and fearful of seeking government services. Layering that fear with the added fear of public scorn would mean that the populations most affected by HIV/AIDS would be the least likely to be tested.

On these grounds, as noted by WHO and UNAIDS in their 2004 *Policy statement on HIV testing*, three underpinning principles of HIV testing (sometimes called the “three Cs”) were established as norms, namely:

- *confidentiality* of test results and of the fact of seeking a test;
- *counselling* and information about HIV/AIDS before and after the test; and

- *consent* to be tested given in an informed, specific and voluntary way by the person to be tested.²

As WHO and UNAIDS emphasize, the primary model for HIV testing in most countries has been one of voluntary counselling and testing (VCT) initiated by clients. However, increasingly, *provider-initiated* testing is being advocated by public health officials in many settings.

WHO and UNAIDS recommend that a *routine offer* of an HIV test be made to pregnant women, people seeking services for other sexually transmitted infections, and asymptomatic persons where HIV is prevalent and antiretroviral treatment is available. However, even when testing takes place as a result of a provider-initiated routine offer, the agencies recommend that there be sufficient pre-test counselling to ensure that there is a good process of informed consent and that people know that *they have the right to refuse a test*.

The WHO/UNAIDS policy distinguishes between *routine offer* and *routine testing*. In practice, however, it may require considerable effort to ensure that offering HIV tests routinely does not turn into an effective testing of everyone who doesn't refuse a test, which would be *routine testing*. WHO and UNAIDS also apparently assume that confidentiality can be preserved in a system of routine offer of HIV tests, but this, too, may require special efforts.

Others have called for a major abridging of the three Cs model. In a widely cited paper, in 2002 De Cock and colleagues called for routine HIV testing that “should not require specific consent or pre-test counselling.”³ In their view, particularly in high-prevalence settings, HIV testing should be the routine or default practice in health facilities, with people having the possibility to opt out of testing.

Increasingly, provider-initiated testing is being advocated by public health officials in many settings.

The rationale of De Cock et al, which has been echoed by others,⁴ is largely an argument against “AIDS exceptionalism.” That is, they say that the protections of human rights of people being tested for HIV provided by the three Cs are no longer justified, if they ever were; and, further, that the three Cs are an impediment to an effective HIV/AIDS response. In particular, they argue that:

- VCT, especially with counselling and informed consent, is too slow and costly to be a useful tool for a public health emergency on the scale of HIV/AIDS, especially in high-prevalence countries;

- HIV/AIDS awareness is already very high in most high-prevalence countries, and therefore there is less need for counselling;
- the exceptional human rights protections related to HIV testing compared to those of other infectious diseases only adds to stigma; normalizing HIV testing and less insistence on anonymity of testing will reduce stigma; and
- VCT actually may undermine social justice in that it restricts people's access to testing, which is essential to treatment and care.

De Cock and colleagues have further suggested that Africa is a special case in terms of needing emergency public health measures unencumbered by “the need to protect individual freedoms.” As they wrote in 2002: “An exceptionalist approach to HIV/AIDS prevention would almost certainly not be applied in the USA or Europe if an epidemic of African severity existed....”⁵

Routine testing raises serious concerns

The arguments of De Cock and others in favour of routine provider-initiated testing, which we take to be motivated by sincere concern for public health, nonetheless raise a number of serious concerns, in our view.

Testing without the three Cs violates human rights

Arguments in favour of models of HIV testing that eliminate or minimize informed consent and counselling generally do not adequately take into account the link between elements of VCT and human rights. All people have the human right to enjoy the “highest attainable standard” of health, which essentially means the

highest attainable standard of health information, goods and services.⁶

The authoritative comment on this right, from the UN committee that monitors governments' progress on attaining this right, suggests that the right to health includes basic services, including HIV/AIDS-related health services, that are “scientifically and medically appropriate and of good quality,” as well as respectful of culture and medical ethics.⁷ We take this to include HIV testing.

The elements of VCT have a clear foundation in human rights law. Informed consent protects the human right to security of the person – that is, to have control over what happens to one's body⁸ – as well as the right to receive information.⁹ Pre-test counselling contributes to the protection of these same human rights. Post-test counselling also imparts information to which people have a right. Confidentiality of test results and of the fact of seeking an HIV test is part of protecting and respecting the right to privacy.¹⁰

The elements of voluntary counselling and testing have a clear foundation in human rights law.

Beyond the components of the testing process itself, governments have a responsibility to ensure that HIV testing, like all other essential health services, is not offered or provided in a way that discriminates against any person or group of people.¹¹ The right to be free of discrim-

ination and the right to security of the person, in our view, also require that in setting HIV testing policy and overseeing its practice, governments take into account the outcomes of HIV testing for people – including stigma, discrimination, violence and other abuse – and do all that they can to prevent human rights violations associated with this health service.

Simply increasing the number of people tested is not a sufficient goal without regard to the consequences of testing

Although there are very few studies of provider-initiated routine HIV testing, it would certainly be no surprise for this practice to yield higher rates of testing than the VCT approach, given that provider initiated routine testing involves testing patients for HIV unless they explicitly state that they do not wish to be tested. But are more tests alone a sufficient achievement? Just the fact of having been tested may not necessarily be a positive outcome if the extra margin of people who are routinely tested includes a significant number who were not well prepared for testing, who do not have adequate information to understand what their test result means for their lives and those around them, who may have irrational fears of HIV because they have had little information about the disease, or who may not know how to begin to disclose their status to sexual or drug-using partners.

Depression, suicide, abandonment, violence and other abuse may result, and these need to be addressed and accounted for in the policy calculus about ratcheting up HIV testing. More research is urgently needed to investigate whether the absence of informed consent and counselling

affects people's experiences of abuse or other negative outcomes as a result of testing HIV-positive.

Few public health professionals would see a greater rate of testing alone as an achievement in itself. Testing for HIV is valuable insofar as it assists with HIV prevention and access to care, treatment and support. Those who call for more provider-initiated routine testing argue that a low rate of testing keeps people who need treatment from getting it and impedes prevention by making it impossible to target safer-behaviour education to people who are HIV-positive but who do not know their status.

The experience of antiretroviral treatment roll-out – even though the roll-out is still less extensive than it should be – has shown that when treatment is available, people generally come forward voluntarily in large numbers for testing. When treatment is unavailable, it is unsurprising that people are reluctant to be tested. It is, moreover, unethical to expose people to the stigma and other negative consequences that may derive from testing without linking testing to other support, treatment and care.

Without the three Cs, testing loses its power as a prevention tool

For testing to be part of a comprehensive, effective and human rights-based prevention effort, it should provide the people tested the opportunity to understand and ask questions about HIV/AIDS transmission and care and to get help on the difficult matter of disclosing their HIV status. HIV testing that includes neither counselling nor informed consent loses its power as a prevention tool. As Heywood has argued, high “awareness” of HIV/AIDS,

including in high-prevalence countries in Africa, is not the same as real knowledge that can guide and inspire behaviour change. This knowledge is much more likely to come through counselling and the chance to ask questions.¹²

HIV testing that includes neither counselling nor informed consent loses its power as a prevention tool.

Counselling was seen from the early years to be an important component of testing, particularly assisting people with well adapted, culturally appropriate information and with the chance to ask questions in a discreet and confidential way. There is no doubt that the absence of qualified counsellors has been a bottleneck at various times, particularly in heavily affected communities. This is a question of resources and program priorities. Many low-income countries have shown that relatively rapid training of HIV counsellors is possible when resources are available.

Has VCT failed, or has it not been adequately financed?

There is a large body of research, including case studies, some of it compiled by the UN, that demonstrates the effectiveness of VCT as part of comprehensive prevention, treatment and care strategies.¹³ Before VCT is pronounced a failure, it is important to understand whether it is the VCT model that has “failed” or whether testing and counselling

have not been adequately supported to realize their potential.

Over the decade from 1988 to 1998, when sub-Saharan Africa should have been building HIV counselling and testing capacity, official development assistance for all HIV/AIDS programs, including testing, was scandalously low and actually declined on a per-HIV-positive-person basis.¹⁴ In this period, with so little hope of offering effective treatment for HIV/AIDS, it is unsurprising that many countries tended to invest in general education programs or promotion of condom use rather than pushing people to be tested.

It is only since 2002, the year in which De Cock and his colleagues declared the failure of VCT, that greater flows of HIV/AIDS assistance through mechanisms such as the Global Fund to Fight AIDS, Tuberculosis and Malaria have opened the possibility for large-scale building of counselling capacity as well as expansion of treatment access.

The growing hope of access to antiretroviral treatment should be seen as highlighting the need for urgent scale-up of counselling capacity to ensure that HIV testing has the preventive value and the strong link to treatment and care that it should have. Scale-up of testing is urgently needed and, with appropriate investment, that scale-up could minimize HIV-related abuse and encourage confidence in the health system that is needed for long-term treatment and care. But that is unlikely to happen outside the VCT framework.

Leaving out the three Cs could increase the negative outcomes of testing

A recent WHO-supported review of 17 studies from Africa and southeast

Asia concludes that from four to 28 percent of women reported negative outcomes following the disclosure of their status. These outcomes included blame, abandonment, violence, anger, stigma and depression.¹⁵ Of these women, between 2.5 percent and 14.6 percent reported having faced violence as a reaction to disclosure of their HIV status.

The authors of this review suggest that some screening of women most at risk of negative outcomes of disclosure – as well as targeted, intensive counselling to help such women, especially those already exposed to domestic violence and sexual coercion – could help women minimize abuse following disclosure.¹⁶ Other researchers have noted that if the two partners in a sexual relationship can be counselled together – which costs more in outreach time and is not always possible – abusive situations may be effectively defused.¹⁷

Even before the WHO review, it was clear that having one's HIV-positive status known carried many risks, especially for women, young people, persons who are already criminalized such as sex workers and people who use drugs, and others who are socially or legally marginalized.

While measures may be taken to mitigate negative outcomes of HIV testing, it is clear that even where the three Cs are respected as a matter of policy, access to such measures is bound to be limited. In addition, for some people, such as women in violent relationships, the only action that may reduce the harm they face from being known to be HIV-positive may be leaving the relationship, which may be impeded by factors that counselling and information cannot address.

Nonetheless, it is important to try to mitigate harms in any way that

is possible with available resources. We hasten to add that even if measures are in place to minimize the negative impact of testing, it remains in our view an abuse of the human rights of people being tested to conduct an HIV test without their informed consent.

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The policy of routine testing is not justified if it exposes people to abuse

In their call for routine testing without informed consent, De Cock et al. recognize that disclosure of HIV status may result in stigma and abuse and suggest that “routine HIV testing should be accompanied by structural changes such as legal and social interdictions against discrimination or abuse of infected people.”¹⁸

The recommendation for strong anti-discrimination measures is a laudable one. But when is it justified to expose people to abuse, including violence, through a public health measure? In cases of epidemics of highly contagious diseases, for example, violating people's freedom of movement by instituting quarantines or their right to informed consent by conducting mandatory screening may be justified in pursuit of the larger goal of protecting the population from disease.

In 1985, a UN human rights body suggested conditions under which it

may be justifiable for a society or for public health authorities to limit or infringe upon human rights to some degree. Among the conditions identified are the following:

- when the limitation on human rights “responds to a pressing public or social need,” “pursues a legitimate aim and is proportionate to that aim”;
- when the limitation represents “no more restrictive means than are required for the achievement of the purpose of the limitation”;
- when the limitation is not applied in an arbitrary or discriminatory manner;
- when the limitation is provided for by law; and
- when the limitation does not violate “non-derogable” rights, which include the right to life; freedom from torture and cruel, inhuman or degrading treatment; freedom from medical or scientific experimentation without free consent; freedom from slavery; and freedom of conscience and religion.¹⁹

In our view, these conditions are not met sufficiently to justify the exposure to human rights abuses that may follow from testing people without their consent and without the counselling that may help minimize violence and abuse. In particular, VCT, when adequately supported by resources, has the potential to be a means of reaching HIV/AIDS prevention and treatment goals that is much less restrictive of human rights than routine HIV testing without consent or counselling.

Testing women in violent unions for HIV, for example, without even trying to apply tools that would

enable them better to protect themselves from violence, may constitute exposing them to cruel and degrading treatment. Increasing investment in counselling of couples would be more effective and less restrictive than routine testing for long-term goals of behaviour change and linking HIV-positive people to treatment and care.

There is no evidence that “routine” testing would reduce stigma and discrimination

Whether routine testing without consent or counselling would reduce stigma and discrimination by treating HIV/AIDS more like other diseases is an empirical question that has not been tested in research. It would be difficult to test such a hypothesis in ethical ways. In countries where certain categories of people – such as all people who enter military service, all prisoners, or all immigrants – are subjected to mandatory or compulsory HIV testing, there is no evidence that suggests that the routinization of testing reduces stigma and discrimination.

In our view, HIV/AIDS does remain exceptional among infectious diseases in the degree to which it is associated with severe, even demonizing, stigma in the public mind and abusive responses from individuals and communities. There remains relatively little investment in most countries in real protection from HIV-related discrimination and abuse, particularly for women, sex workers, men who have sex with men, people who use drugs and prisoners.

Even where protection against discrimination on the grounds of HIV/AIDS status is well established in the law, it is sometimes undermined by the use of criminal law related to HIV transmission and exposure.

There is little reason to believe that the routinization of testing would be effective in combating the wide range of forms and instances of HIV-related discrimination and abuse. Moreover, knowing the health system is testing people for HIV without counselling and consent might very well discourage people from seeking care and make them suspicious of health professionals with whom they need a relationship of confidence.

Increasing investment in counselling of couples would be more effective and less restrictive than routine testing.

Conclusion

For years the world somehow tolerated the idea that people in wealthy countries would be treated for HIV/AIDS and those in resource-poor countries would have to get by with “low-cost” prevention measures and palliative care. This idea was undoubtedly partly a function of the high cost of antiretroviral treatment. After years of activism, treatment – while still too inaccessible – is now recognized as the right of all people living with HIV/AIDS. Efforts have been made not only to scale up treatment access but to lower the costs of treatment.

There is no doubt that effective voluntary counselling and testing are also costly. But both are essential to an effective HIV/AIDS response, and both are human rights obligations

of governments. If there is a way, through better HIV counselling and outreach efforts to increase counselling of couples, to reduce abuse and violence against HIV-positive persons and to increase confidence in health services – even if this is more expensive than simply testing everyone who comes to a health facility without explicit consent – this investment must take place.

It is increasingly recognized, moreover, that all aspects of an effective HIV/AIDS response, including treatment, require greater investment in the training and retention of health workers and in health infrastructure.²⁰ Building counselling and testing capacity goes hand in hand with building capacity for treatment and care.

It is crucial that HIV testing be scaled up, but it is equally crucial that this scale-up be done in a manner that minimizes harm and maximizes benefits. In our view, this will happen when scaling up HIV testing is understood to mean scaling up of the capacity of health systems both to respect people’s right to consent to a medical procedure that has great consequences in people’s lives, and to give them as much information as possible to protect themselves from abuses that may accompany the knowledge of their HIV status. Like combination antiretroviral therapy, this will cost money. Like combination therapy, it is indispensable and is the human right of all people.

– Joanne Csete and Richard Elliott

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¹ UNAIDS and WHO. *UNAIDS/WHO policy statement on HIV testing*. 2004. Available at http://www.who.int/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf.

² *Ibid.*

³ K De Cock et al. Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *Lancet*, 2002; 360: 70. Dr. De Cock will be the director of the HIV/AIDS Department at the WHO's Geneva headquarters as of March 2006.

⁴ R Holbrooke and R Furman. A global battle's missing weapon (op-ed). *New York Times*, 10 February 2004: A35.

⁵ *Ibid.* at 69.

⁶ *International Covenant on Economic, Social and Cultural*

Rights. United Nations General Assembly Res. 2200A, 16 December 1966, article 12(1). See also interpretation of this right in UN Committee on Economic, Social and Cultural Rights. General Comment No. 14: The right to the highest attainable standard of health: Art 12 E/C.12/2000/4, 11 August 2000.

⁷ General Comment No. 14 at paras 12c and 12d.

⁸ *International Covenant on Civil and Political Rights*. United Nations General Assembly Res. 2200A, 16 December 1966, article 9(1).

⁹ *Ibid.* at article 19(2).

¹⁰ *Ibid.* at article 17(1).

¹¹ *International Covenant on Economic, Social and Cultural Rights*, article 2(2).

¹² M Heywood. Human rights and HIV/AIDS in the context of 3 by 5: time for new directions? *Canadian HIV/AIDS Policy & Law Review*, 2004; 9(2): 1, 7-13.

¹³ See, e.g., research summaries by USAID at www.usaid.gov/our_work/global_health/aids/TechAreas/voluntarycounsel/vct_research.html and by Family Health International at www.fhi.org/en/hivaids/pub/fact/vctforhiv.htm.

¹⁴ A Attaran and J Sachs. Defining and refining international donor support for combating the AIDS pandemic. *Lancet* 2001; 357(9249): 57-61.

¹⁵ A Medley et al. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization*, 2004; 82(4): 302.

¹⁶ *Ibid.* at 305.

¹⁷ Voluntary HIV-1 Counseling and Testing Efficacy Study Group. Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania and Trinidad: a randomised trial. *Lancet* 2000; 356(9224): 103-112.

¹⁸ De Cock et al at 71.

¹⁹ UN Economic and Social Council, UN Sub-Commission on Prevention of Discrimination and Protection of Minorities. *Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights (Annex)*. UN Doc E/CN.4/1984/4 (1984), articles I.A., II.D.

²⁰ T Rosenberg. Think again: AIDS. *Foreign Affairs* 2005; March/April: 22-26.