Routine testing for HIV – ethical and legal implications

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Judge Edwin Cameron has suggested that because of the high level of ignorance about people’s HIV status and the stigma attached to it, and as HIV infection can now be controlled through the use of antiretroviral drugs, the time has come to review the present ‘opt in’ approach to HIV testing and counselling. He suggests that an ‘opt out’ approach should be adopted whereby people receiving medical treatment should have their blood automatically tested for HIV unless they specifically opt out from doing so. He argues that this can be done provided three conditions are satisfied: (i) antiretroviral treatment must be made available for offer to the patient; (ii) there must be assurance that the consequences of diagnosis will not be discrimination and ostracism; and (iii) the patient must be secure in the confidentiality of the testing procedure and its outcome.

The present ‘opt in’ approach requires extensive counselling before HIV testing of patients and places a heavy burden on health care resources. It also inhibits people from undergoing tests because of the stigma attached to being diagnosed as HIV positive. An ‘opt out’ approach requires less extensive counselling and treats the test for HIV infection like that for any other sexually transmissible infection such as the routine testing of pregnant women for syphilis – unless the patient specifically refuses to be tested. Under the ‘opt out’ approach counselling may be done in groups or by giving patients a pamphlet or requiring them to sign a form. The high court has held that at present such conduct does not satisfy the counselling requirement for HIV testing, and that proper extensive individual counselling must be done in order to obtain an informed consent. The National Department of Health, the Health Professions Council of South Africa and the South African Medical Association have taken the same approach.

Research has shown that the adoption of an ‘opt out’ approach could reduce public resistance to HIV testing and increase the number of people who know their HIV status.

This may lead to a rise in the uptake of people who seek access to antiretroviral treatment, as has happened in Botswana.

Judge Cameron’s suggestion would mean moving away from the present ‘opt in’ approach and its stringent requirements for HIV testing and counselling, and regarding informed consent procedures for HIV infection like those of any other dread disease such as hepatitis B or diabetes. It has been argued that an ‘opt out’ approach undermines the concept of voluntariness in HIV policies, particularly in resource-poor countries where people are likely to be coerced into HIV testing by health care professionals. For this reason it is necessary to consider the likely ethical, constitutional and legal implications of such an approach in the South African context.

Ethical, constitutional and legal implications

The ethical, constitutional and legal implications of an ‘opt out’ approach can best be dealt with within the framework of the basic biomedical ethical principles of patient autonomy, beneficence, non-maleficence and justice.

Patient autonomy

Patient autonomy is the ethical principle that recognises that patients have the right to decide for themselves what they want to do with their bodies. The principle of autonomy is reflected in the Constitution in the rights to dignity, life, bodily integrity and privacy. The principle is also found in the National Health Act, the rules of the Health Professions Council of South Africa and the common law in the provisions dealing with informed consent and confidentiality. The courts have required that informed consent for HIV testing purposes must include extensive individual pre-test counselling based on an ‘opt in’ approach.

An ‘opt out’ approach would have to ensure that patients receive sufficient information regarding the nature, effect and consequences of an HIV test to enable them to decide whether or not to consent to or assume the risk of harm involved – without subjecting them to extensive counselling as is currently required. Pamphlets, posters or group counselling may be sufficient if patients have enough information to enable them to give or refuse consent in the same manner as for any other medical test that is conducted on patients on an ‘opt out’ basis. In addition their right to confidentiality would have to be assured. Such an approach would be consistent with the
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Beneficence

Beneficence is the ethical principle that requires doctors and health practitioners to do good for their patients. This is reflected in the Constitution by the provision that everyone has the right of access to health care services. The principle of beneficence was apparent in the Constitutional Court judgment regarding the provision of prophylactic treatment to pregnant women and babies to prevent neonates contracting HIV. The National Health Act also echoes the beneficence principle by requiring state-funded health departments to ‘provide health services within the limits of available resources’.

The adoption of routine HIV testing would be consistent with the principle of beneficence as it would enable people who discover that they are HIV positive to seek antiretroviral treatment timeously. It will overcome the problem of people being ignorant of their HIV status. Ignorance of their HIV status often results in HIV-positive people only seeking treatment when they have already progressed to the end stages of full-blown AIDS – by which time it may be too late. The ‘opt out’ approach regarding testing for HIV will also be in line with the Constitution because it will enable HIV-positive people to access health care services regarding antiretroviral drug treatment in time to save their lives – as well as to modify their sexual behaviour to save the lives of others. In order to be constitutionally acceptable – if the resources are available – access to antiretroviral treatment must be provided to patients who test HIV positive and require it.

Non-maleficence

Non-maleficence is the principle that requires doctors and health practitioners not to harm their patients. This principle is reflected in the Constitution, which provides that nobody may be refused emergency medical treatment and that everyone has a right to ‘an environment that is not harmful to their health or well-being’. These provisions are also to be found in the National Health Act. An ‘opt out’ approach will be in line with the non-maleficence principle, particularly in respect of rape survivors and other patients at risk of being HIV positive.

Routine HIV testing of rape survivors forced to have unprotected sex is consistent with the non-maleficence principle because a negative test result gives rise to a medical emergency and the urgent need for post-exposure prophylaxis if the perpetrator may be HIV positive. Routine HIV testing of other patients will also be in accordance with the non-maleficence principle because it will ensure that those who test positive are not exposed to an environment that is harmful to their health or well-being. Once HIV-positive people know their status they can access antiretroviral treatment when they need it. They can also take steps to avoid infecting others and to prevent themselves being reinfected. In order to be consistent with the Constitution – provided the resources are available – antiretroviral treatment must be made available to patients who test HIV positive and require it.

Justice

The ethical principle of justice requires that all patients are treated equally and fairly. The Constitution provides that nobody may be unfairly discriminated against on ‘one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth’. These grounds are not the only bases for discrimination, and the Constitutional Court has held that HIV status may also be a ground for discrimination.

It can be argued that HIV-positive people are not treated equally or fairly compared with other people afflicted with deadly diseases that can be controlled through routine testing and medication. The stigma attached to HIV infection discourages people from undertaking HIV tests, and the onerous pre-test counselling requirements place an undue burden on health care providers. The result is that the majority of HIV-infected people do not know their HIV status and do not take steps to control it. In addition health care providers spend so much time pre-counselling individual patients that they can only conduct comparatively few HIV tests on a daily basis. This ‘drains healthcare resources away from diagnosis and treatment of HIV’. People faced with other dread diseases are not faced with these obstacles and as they can rely on routine testing to identify their condition without being stigmatised, they can be attended to timeously by health care providers.

In a sense the current ‘opt in’ approach to HIV testing, with its onerous counselling procedures and the stigma associated with HIV infection, has led to HIV-positive people being unfairly discriminated against because they have been discouraged from learning their status, and as a result have been prevented from accessing life-saving treatment. An ‘opt out’ approach would encourage them to do so by making it easier and less stigmatising, and would be consistent with the principle of justice and fairness. The result would be that HIV-positive people would be treated like any other patients suffering from a potentially life-threatening disease who are subjected to routine testing for their own protection. As mentioned by Judge Cameron, people who test HIV positive under an ‘opt out’ approach should not be unfairly discriminated against or ostracised.
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Is it reasonable and justifiable to legislate for routine testing for HIV infection?

It has been argued that introducing an ‘opt out’ approach to HIV testing would be consistent with basic biomedical ethical principles, the Constitution and national legislation. However, if it is suggested that an ‘opt out’ approach is not consistent with the autonomy principles9 of the Constitution regarding bodily integrity and privacy,10 could it be argued that a law to introduce routine testing for HIV would be reasonable and justifiable? The Constitution provides that fundamental rights in the Constitution may only be limited if such limitation is of general application to the people concerned, and is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom.11

A law of general application means that the law must be sufficiently clear, accessible and precise for those affected by it to know the extent of their rights and obligations.12 For example, if an ‘opt out’ approach is provided for in legislation the law would have to explain what is meant by routine testing and how people can opt out of it. The reasons for the limitation of any constitutional right must be acceptable to an open and democratic society based on human dignity, equality and freedom. It can be argued that an ‘opt out’ approach to HIV testing is reasonable and justifiable because it has been adopted in Botswana,3 and for women attending antenatal clinics in Canada, the UK and the USA.4 These countries are generally regarded as open and democratic societies based on human dignity, equality and freedom.

In order to satisfy the limitation requirements, the harm caused by the infringement of a constitutional right must also be proportional to the benefits to be achieved by the law.13 For example, any legislative interference with the autonomy rights of bodily integrity and privacy that may flow from requiring patients to ‘opt out’ of HIV testing would have to be less harmful than the purpose of the law. Under the ‘opt out’ approach the harm done to the rights of bodily integrity and privacy of patients is that patients are required to explicitly refuse an HIV test rather than request one. The purpose of the law is to enable people to discover their HIV status without being stigmatised so that they can access treatment to save their lives and modify their sexual behaviour to save the lives of others. On balance therefore it can be strongly argued that the harm caused by shifting the onus of refusing consent is outweighed by the potentially life-saving benefits to HIV-positive patients.14 As a result the limitation is reasonable and justifiable in terms of the Constitution.

Conclusion

It is submitted that routine testing for HIV infection, using an ‘opt out’ approach, is consistent with the basic biomedical ethical principles of patient autonomy, beneficence, non-maleficence and justice. Such testing is also in line with the Constitution and other laws. Even if it were argued that an ‘opt out’ approach violated the Constitutional rights to bodily integrity and privacy such infringements would be reasonable and justifiable and therefore in accordance with the Constitution. As stated by Judge Cameron, in all instances ‘the testing procedure and its outcome’ must be subject to the usual rules regarding confidentiality.15

References

2. C v Minister of Correctional Services 1996 (4) SA 292 (T).
7. Stanley B, Fraser J, Cox NH. Uptake of HIV screening in gynaecological medicine after change to ‘opt out’ consent. BJM 2003; 326: 1574.
11. Sections 10 (dignity), 11 (life), 12 (bodily integrity) and 14 (privacy) of the Constitution of the Republic of South Africa Act No. 108 of 1996.
12. Sections 7 (consent) and 14 (confidentiality) of the National Health Act No. 61 of 2003.
17. cf. Castoll v De Groef 1994 (4) SA 408 (CC) at 425.
20. Section 3(2) of the National Health Act No. 61 of 2003.
22. Sections 5 and 2(5)(ii) of the National Health Act No. 61 of 2003.
29. cf. S v Molosomye 1995 (3) SA 331 (CC) at paragraphs 104

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To all medical specialists,

At Discovery Health, we believe the South African private health care industry is a national asset. We believe that health care professionals are the key to ensuring that it grows and thrives. In fact, we have an important goal in common with you: to give our members, your patients, access to quality health care that is affordable and sustainable.

We want to engage positively with you.

I have personally met with many specialists and representatives associations over the last six months. These meetings are part of a sincere and focused effort to find ways to work with you, and to enhance your experience when interacting with Discovery Health.

Our objective is to pay you more, simplify administration and support the health care profession.

Going into 2007, we set ourselves these clear objectives:

1. To pay doctors more on a sustainable basis, recognizing the value and role that you play;
2. To reduce the unnecessary administrative burden that is placed on health care professionals every day;
3. To engage with health care professionals on clinical issues to ensure that our protocols are fair, sound and rigorous.

With advances in medical technology, the quality of health care being offered to Discovery Health’s members is getting better all the time. The challenge that we are facing is that members’ premiums are constrained by affordability.

As a health care funder, it is up to us to balance these opposing factors.

If members are satisfied with the medical scheme cover and doctors receive adequate remuneration, we will have a system that meets members’ expectations and keeps doctors up to speed on practicing medicine.

This was the thinking behind the Premier Rate for specialists which has produced a broad range of responses from the specialist market. Many doctors who were previously billing at the Discovery Health rate are now receiving up to 50% higher remuneration directly and members now have certainty that they will experience no co-payments.

While it is difficult to find a “one-size-fits-all” solution, we are encouraged that most specialties are billing at the Premier Rate, increasing remuneration by 35% on average.

However, we want to satisfy the needs of all specialists and are constantly engaging at an individual and representative society level to find solutions to achieve this.

We are engaging at a society level with the intention of working together to achieve these common objectives.

Finding the right solutions is not an easy task, given the complex dynamics that exist in the environment. However, you have my personal commitment that we are focusing on these issues with urgency and with a will to bring about rapid, positive change. I believe that through an approach of mutual respect and engagement, we can make significant progress.

We are also looking beyond remuneration to improving the service that health care professionals receive from Discovery Health and engaging with health care professionals on clinical issues to ensure that our policies and protocols are rigorous, sound and fair to all parties.

I welcome any opportunity to engage with you at practice or society level to ensure that we achieve the objectives I have outlined here.

Kind regards,

Nelita Koopmans
CEO, Discovery Health

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