

# Common ethical issues related to HIV/AIDS

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## Opt-in or opt-out: approaches to HIV testing

South Africa is the epicentre of the human immunodeficiency virus (HIV) pandemic.<sup>1</sup> Based on a wide range of data, including household and antenatal studies, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that HIV prevalence was 17.8% among 15-49 year-olds at the end of 2009. Their high and low estimates were 17.2% and 18.3% respectively. According to their own total population estimation, this implies that at the end of 2009, around 5.6 million South Africans were living with HIV, including 300 000 children under 15 years old.<sup>2</sup> The national prevalence of HIV is around 11%. In 2008, an estimated 5.2 million people were living with HIV and acquired immune deficiency syndrome (AIDS) in South Africa, and it is believed that over 250 000 people died of AIDS. AIDS is a major factor in the overall rising number of deaths. Around 70 000 babies are born with HIV every year.<sup>3</sup> Statistics South Africa (SSA) reveals that the annual number of deaths rose by 93% between 1997-2006. Among those aged 25-49 years, the rise was 173% in the same nine-year period. The overall increase in the number of deaths, as reported by SSA, is attributed to population growth. However, as they point out, these figures do not clarify the disparity in the rise in deaths among people aged 25-49 years.<sup>4</sup> It is believed that AIDS-related deaths are underestimated because many doctors avoid mentioning the cause of death on the death certificates.

Thirty years since HIV/AIDS began to ravage humans, we can state two related facts. Firstly, we all wish HIV to be curbed, and hopefully, to disappear. Secondly, the optimal way to achieve this is to be tested. At the heart of the matter is the question: what approach to HIV testing should be employed?

Generally, two approaches to this question are utilised, namely the human rights approach (opt-in), and the public health approach (opt-out). The human rights approach defends "selective testing", based on the principle that it is every one's right to agree or decline to be tested, and to disclose, or not, the result, if positive.<sup>5</sup>

Importantly, to gain access to the healthcare support system, an individual has no choice but to be tested. Here, it should be noted, that access to health services, and HIV educational and support systems, are generally more accessible to those living in suburban, as opposed to rural areas.<sup>6,7</sup> The 2008 National Strategic Plan's aim is for one quarter of the general population to take the test every year by 2011.<sup>8</sup> According to the latest information found in Draft Zero for Consultation of the *National Strategic Plan for HIV and AIDS, sexually transmitted diseases, and tuberculosis, 2012-2016*, by June 2011, an "estimated 14.8 million counselling sessions, and 13 million tests for HIV were conducted."<sup>9</sup> This part of the article examines some of the benefits and shortcomings of the opt-in and opt-out approaches to HIV testing.

### The opt-in approach

Currently, the opt-in approach to HIV testing is used in South Africa. The opt-in policy, also known as the human rights approach, or voluntary counselling and testing (VCT), recommends that individuals should decide voluntarily whether or not to be tested. Although counselled to do so, the opt-in approach also asserts that HIV-infected persons have the right to decide whether or not to disclose their HIV status. The opt-in approach argument is grounded on an individual's right to dignity, worth, and respect with regard to their autonomous decisions. When this approach is enacted, the ethical responsibility to take what he, or she, considers to be the right course of action regarding a positive or negative result after testing, rests with the individual.

### The opt-out approach

The public health approach supports “universal” testing. It recommends that everyone attending a healthcare facility should be offered an HIV test. The World Health Organization (WHO) recommended the public health approach in 2007.<sup>10</sup> This has been perceived as a fundamental shift away from the human rights approach. While recognising that HIV/AIDS deeply affects the infected individual's physical, emotional, professional, and societal life, the public health approach advocates that HIV/AIDS also profoundly impacts on society at large, e.g. in terms of sexual partners, families, the workforce, and the economy. From this perspective, HIV/AIDS cannot be viewed as a strictly private matter only. This policy allows an individual the right to decline. In cases where undergoing testing is agreed to, pre- and post-test counselling is compulsory. In this way, an individual's human rights are fully respected and protected.<sup>11</sup>

The opt-out approach has a number of benefits. Individuals who are unaware of their seropositive status are given the opportunity to, hopefully change their lifestyle, disclose their status where necessary, and receive treatment. This approach also potentially provides for the diagnosis of HIV at an earlier stage. This option is recommended for general implementation in populations where more than one per cent of pregnant women are seropositive. All patients with a clinical presentation that might result from HIV, such as tuberculosis and suspected tuberculosis, must be offered the test. The WHO also states that all preconditions, i.e. the availability of counsellors, laboratory facilities, and antiretrovirals, should be met to implement the opt-out policy. As early as 2004, the Centers for Disease Controls (CDC) recommended HIV testing for all 13-64 year olds attending a health facility. In this study, four out of five individuals agreed to be tested.<sup>12</sup>

The opt-out policy has been shown to be widely accepted. In Uganda, half of the persons undergoing opt-out testing tested positive; and 83% of them were unaware of their status.<sup>13</sup> In Zambia, the policy was implemented with regard to more than 10 000 children attending a paediatric facility with a parent or guardian. The acceptance rate was 80%; 20% tested positive. The positive cases were diagnosed at an earlier stage, and with higher CD4 counts.<sup>14</sup>

In terms of fiscal and human resources, testing is the only way to understand and logistically plan to curb the pandemic. The WHO approach fully respects an individual's right to decline, and equally respects the duty to provide counselling services. Although public health policies are known to target the best interests of the public at large, the

opt-out approach also manages to protect individual rights, as well as promote the public good.

Both the opt-in and opt-out approaches to HIV testing carry the hope that more people will behave responsibly, inform, and protect, their partners and children. The opt-in policy insists that the HIV-infected person has a right to confidentiality and protection against unfair discrimination. Indeed, these are fundamental human rights that must be protected. Yet, the opt-in approach provides no recommendation on how to prevent harm to others, inflicted through transmission of the virus. This is because a rights-based approach is based on a single individual. The opt-out approach presents a means by which HIV can be epidemiologically documented, so that resources can be better applied. It also permits that the final decision, to be tested or not, lies with an individual. Of the two options, we suggest that the opt-out approach carries greater ethical weight, when considering the social and economic burden of HIV upon our limited healthcare resources.

### HIV and stigmatisation

In South Africa, HIV remains mainly a heterosexually sexually transmitted infection. The roles of culture, religion and belief systems are inexorably entwined with the social conceptions of those who are infected and affected by HIV. The problem of stigmatisation is a major issue, and is generally included in all HIV debates. The question, then, is: what is stigmatisation, and what is its magnitude. It is said

that the most disadvantaged areas in the country tend to fall outside the areas in which HIV education and treatment access are most available. They may also be areas in which cultural and religious perceptions, e.g. gender inequalities and concepts of disease as a “sin”, are more prevalent, as opposed to those of people living in urban or metropolitan regions.<sup>15</sup> How to best provide for the needs of communities in the face of HIV, 30 years on, remains a challenge.

A stigma is a mark of disgrace. A stigma may be real, or perceived. In the context of HIV, a person whose seropositive status is known by relatives, friends, or co-workers, may be victimised, rejected, or become the object of malicious gossip.<sup>16</sup> This is real stigmatisation. Despite educational initiatives, a major contributing factor to stigmatisation is the fear of death. HIV/AIDS is a life-threatening disease, and people are afraid of contracting it. In addition, HIV-positive persons are often considered by society to be individually responsible for contracting HIV. Gender roles, religion and cultural norms can contribute to stigmatisation.<sup>17,18</sup> The fear of stigmatisation is a major justification for non-disclosure of

HIV-positive status, which, in turn, has impeded control of the pandemic.<sup>19,20</sup> Fear of stigmatisation is so profound that HIV/tuberculosis patients reportedly decline antiretroviral treatment (ART).<sup>21</sup> Moreover, with regard to mother-to-child-transmission, stigmatisation is the supposed reason why mothers risk both their lives, and that of their foetus or new-born, by refusing ART.<sup>22,23</sup> In particular, gender-based power imbalance is also a major contributing factor to the stigmatisation of women who are HIV seropositive.<sup>24</sup>

A stigma is perceived when people believe, or have the false impression, that society is stigmatising them for one reason or another, when in fact, it is not. In this context, this would pertain to the perception of HIV-seropositive persons who are being stigmatised.<sup>25</sup> For instance, homosexuals used to be the victims of real stigmatisation in many countries. Fortunately, this longer seems to be the case. In other words, societal views have evolved with regard to homosexuality.

Since stigmatisation is the cornerstone upon which the opt-in approach rests, it is important to assess the magnitude of the problem. An interesting survey on stigmatisation was carried out in two South African communities.<sup>26</sup> The commonality between the two is the cultural and linguistic background. The difference was that one was suburban, and the other rural. In the former, the rate of disclosure to the household was high, and in the latter, low. The difference was attributed to the availability of social and medical support services in the suburban community, and the lack thereof in the rural one. Furthermore, disclosure was motivated by the infected individuals' need for assistance.

A recent South African survey confirmed that stigmatisation is more perceived, than real.<sup>27</sup> The WHO published a meta-analysis of disclosure by women to their partners in 22 industrialised and 19 developing countries (17 in sub-Saharan Africa).<sup>28</sup> The disclosure rate was 79% in the former, and 49% in the latter. After disclosure, the rate of violence against women varied between 0.4-4.0% in the industrialised, and between 3.5-4.0%, in the developing countries. Evidence showed that, although real, stigmatisation and violence resulting from disclosure, was not of the expected magnitude .

Since 1995, despite accumulating evidence against real stigmatisation, South Africa has enacted 10 acts, policies, codes, plans, and frameworks, concerning unfair discrimination on the grounds of HIV-seropositive status, and its disclosure. All of these mechanisms emphasise the constitutional right to privacy that grants an individual the right to choose whether or not to disclose his or her status. Of course, the right to privacy must be protected.

Stigmatisation is not reliant on, or does not result from, a specific testing policy. Rather it is a social phenomenon, and in a clinical setting, may link to a confidentiality breach. With the great number of individuals infected and affected by HIV/AIDS, and the accompanying concern of individuals concerning possible stigmatisation, when in consultation, doctors should consider it their duty to openly discuss this issue with their patients.

### **Criminalisation of exposure to and transmission of HIV**

Regardless of the considerable education, time, and resources extended to fight HIV/AIDS, it is clear that certain infected individuals are unprepared to undergo testing, or to disclose their status to their sexual partners. This defeats prevention efforts. This is why some countries have decided to criminalise the deliberate exposure, and transmission of, HIV. There is widespread concern that existing prevention policies have failed to curb the spread of HIV.<sup>29</sup> This has led to a proposal that wilful exposure to HIV should be criminalised. This is in conflict with the human rights approach. It also creates a significant difficulty in defining whom, when, and why, someone should be indicted lawfully. In such debates, the moral responsibility of those who spread the infection is not discussed, whereas approaches to curb the spread of HIV are.<sup>30</sup>

Criminal laws exist to protect society from harm, and to sanction the perpetrator of the harm. The goals of criminalising certain actions are to protect society in general, and vulnerable populations, in particular; and to seek justice for the victims. In the case of HIV, there is a debate whether or not criminal laws should be HIV-specific. In the United States, more than half of the states have criminalised the act of an infected individual having sexual intercourse.<sup>31</sup> This was brought about mainly because of people's failure to disclose their HIV-positive status to their sexual partners.

Recently, a number of West African states have adopted this idea.<sup>32</sup> Notably, some legislation criminalises the vertical transmission of HIV from mother to child.<sup>33</sup> Between these extremes, some international bodies have suggested that criminal sanctions should only apply if the victim actually becomes infected with HIV.<sup>34</sup>

The difficulty concerns the following questions. In what circumstances is the transmission of HIV a criminal offence? And, what are the costs and benefits of criminalisation?

To be a felony, the transmission of HIV must be wilful, and carried out with the full knowledge of one's HIV-positive status. That sounds straightforward, but it raises a series

of questions. The UNAIDS supports legal action if it can be established that the intent to cause harm can be proved beyond reasonable doubt, and that the transmission actually did occur.<sup>35</sup> This view is controversial. In many courts, the fact that a murderer intended to kill, but only wounded the victim, would still be considered to constitute a felony.

Furthermore, it is hard to prove beyond reasonable doubt that the perpetrator had prior knowledge of his or her status, and intended to transmit the infection. In addition, in some countries, laws prohibiting HIV-infected persons from having intercourse, do not state whether condom use is considered to be a sufficient defence against protection from prosecution. In addition, how can it be proved that a condom was actually used?

From the victim's point of view, two possibilities exist. Either he or she was already infected, or not. In the latter instance, how can it be proved that the seroconversion resulted from the perpetrator's body fluids, as opposed to those of someone else? Deoxyribonucleic acid testing has helped to resolve numerous crimes. Unfortunately, phylogenetic analysis of HIV genes is unable to establish a definitive match between HIV samples. It can only establish a degree of relatedness.

Depending on the country, a legal approach has numerous hurdles, as well as a multitude of divergent legislation. In most countries, the voluntary and reckless infliction of harm is a crime. Here, the establishment of a crime may be more complicated, as it could be argued that consensual and protected sex between concordant or discordant adults is permissible. On the other hand, based on the laws of a particular country, this may not be arguable.

The Southern African Development Community's Article 15.4 of 2008 lists five conditions that need to be met in order for a person's HIV-positive status to be disclosed. Among them, features "when there is a risk of immediate harm to a third party".<sup>36</sup> This implicitly confirms that the transmission of HIV constitutes harm. The voluntary infliction of harm is a felony. Therefore, the voluntary (as in full knowledge of one's HIV-positive status) transmission of HIV is a crime. The unanswered question is how to prove it beyond reasonable doubt.

The other aspect of criminalisation pertains to balancing its costs and benefits.

The main arguments of opponents to criminalisation are:

- It would constitute a disincentive to VCT
- It would further fuel stigmatisation
- It would further marginalise vulnerable populations

- Under this provision, people with high-risk sexual behaviour would avoid knowing their status to prevent prosecution
- It would increase the risk of acquiring and spreading HIV in prisons.<sup>37</sup>

The second point would apply to the category defined in the fourth point only. While a factor, the stigmatisation issue, should be further investigated as real or perceived, and addressed accordingly. The third point is a rejoinder of the second point. Granted that inmates have rights and personal dignity that demands respect, it does not give them the right to commit sexual offences.

It would appear that the arguments against criminalisation are the same as those against stigmatisation. They perpetuate what they claim to prevent, that is, the spread of HIV.

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