Self-testing without counselling

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“Home testing may not provide the final solution, and a more comprehensive HIV prevention strategy will be required; however, it may prove an effective tool to increase social awareness of HIV when used hand-in-hand with voluntary counselling and testing.”

Promoting self-testing for HIV in developing countries: potential benefits and pitfalls

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The prevalence of the human immunodeficiency virus (HIV) in developing countries is a growing problem. By 2003, an estimated 38 million people worldwide were infected with HIV, with approximately 14,000 new infections occurring each day. Some 2.3 million children worldwide are infected with HIV and they account for 18% of all deaths related to the acquired immunodeficiency syndrome (AIDS). The need to add to the discussion on preventive measures for reducing the prevalence and incidence of HIV by weighing the potential benefits of promoting self-testing for HIV in developing countries and the concerns that need to be raised.

Research reveals two common reasons why people do not attend HIV counselling: limited HIV testing services, and social stigma and discrimination associated with HIV infection. Both these factors play a prominent role in the lack of HIV awareness among people in developing countries and may lead to errors in HIV reporting. People living in remote areas remain unscreened if local testing services are not available; because they cannot afford the time involved to go to far-off facilities and the consequent loss of pay. Other concerns such as lack of privacy, overcrowded clinics and physicians’ reluctance to test are cofactors in low screening rates. Self-testing will help overcome these objections and is a convenient option compared with the conventional methods of testing.

People’s ignorance of their HIV status creates serious problems. Research shows that approximately 25% of HIV-positive people in the United States are transmitting the virus to others, as they are unaware of their status. This proportion is likely to be higher in developing countries, in view of lower literacy rates. Mads et al. report from their study in the United States that people modify their behaviour and engage in fewer high-risk sexual encounters once they know they are HIV positive. Because it is easy to use, self-testing can help more and more people to know their HIV status; they might modify their behaviour and thus contribute to lowering the incidence of new cases. Home testing of HIV could transform the landscape of dating and also affect other safe-sex practices by encouraging would-be partners to learn each other’s HIV status before having sex. Self-testing of HIV could thus play a very important public health role by decreasing the sexual transmission of HIV; preliminary studies show that 80% of people whose positive results were detected by a rapid test in a hospital, emergency department or a clinic sought care.

Some researchers have examined the merits of self-testing and the need to increase its availability. Späth et al. report that self-testing is a quick and cost-effective method for HIV detection and may prove beneficial in both industrialised and developing countries; they explain the benefits of one self-testing kit for HIV in detail. The US Food and Drug Administration (FDA) has agreed to consider the sale of home-testing kits for HIV and a few social organizations, such as the San Francisco AIDS Foundation, also support their introduction. Similar steps should be taken in other countries, especially the developing ones, to tackle the growing menace of HIV infection.

To support the introduction of home-testing kits in developing countries demands a collective effort from organizations such as WHO, UNESCO, local government agencies and local social groups. It is important that efforts should be made to make information about self-testing methods freely available. It is also essential to provide self-testing kits at reasonable prices so that cost is not a barrier to use in areas that are already plagued with poverty and lower standards of living. In such parts of the world, providing free or discounted samples may prove beneficial.

Home-testing kits alone are not sufficient: the purpose of increasing HIV awareness will only be achieved if pre-test and post-test counselling are provided. At HIV testing clinics, the outcome is usually delivered in person: in the event of a positive test result, an expert is on hand to provide assistance and information. The manufacturers of home tests should provide telephone counselling facilities with toll-free numbers and referral information with the testing kit, as well as a web site that contains exhaustive information concerning the kit and answers to frequently asked questions about it. It could also furnish the contact details of local social organizations that provide counselling, as a client would have the choice of either contacting the organization by telephone or going there personally for assistance. Although telephone counselling is not as effective as personal interaction, in some cases the anonymity offered by the telephone service may make it easier for a person with a positive test result to open up and reveal distressing feelings and information.

A study by Frank et al. reports that anonymous HIV home collection kits with pre-test and post-test telephone counselling can provide a safe and effective alternative to conventional testing methods. Numerous studies document the effectiveness of telephone counselling in crisis intervention and suicide prevention. Although Dwight et al. report that no increase in suicide rates was observed after home-testing kits were approved by
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THE LEGAL, ETHICAL, GENDER, HUMAN RIGHTS AND PUBLIC HEALTH IMPLICATIONS OF HIV SELF-TESTING SCALE-UP

8-9 April 2013
Brocher Foundation
Geneva, Switzerland

A short technical update on self-testing for HIV
REPORT ON THE FIRST INTERNATIONAL SYMPOSIUM ON SELF-TESTING FOR HIV: THE LEGAL, ETHICAL, GENDER, HUMAN RIGHTS AND PUBLIC-HEALTH IMPLICATIONS OF HIV SELF-TESTING SCALE-UP

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ACCESS TO HIVST

Open Access

- Vending Machine

“Unsupervised” HIVST

- Available OTC, e.g. pharmacies, groceries.

Semi-Restricted

- Community health worker distribution

“Supervised” HIVST

- Supervised by health worker in facility

Clinically-Restricted

- Unsupervised in facility

Community health worker supervision
What’s the concern?

- There is increased risk of unmanaged anxiety, with potential for suicide
  
  “SAMA chairman ... noted that it was ‘risky’ for individuals to test themselves ‘unmonitored’ and that it might lead to devastated patients or suicide”.

- Counselling is a vital component of HIV tests and is bypassed by self-testing

- Testing could be coerced in a home environment

- Accuracy of test
Inconsistency

There are a wide range of self-tests currently available in pharmacies and supermarkets in SA, including tests for pregnancy, prostate cancer, ovulation, recreational drugs and breathalysers for alcohol. Few objections have been raised against the availability of these tests, and their distribution is not regulated.
Children – a particular challenge

“…simply offering self-HIV tests to all children aged >12 years would not be lawful, unless it could be shown that it was in their best interests and that counselling was provided.”

Health facility-based HIV counselling and testing does not capture all children and adolescents who are at risk of HIV infection. Self-testing involves conducting an HIV test at home or in any other convenient space without the involvement of a third party. It is increasingly being argued that it should be incorporated into routine HIV prevention programmes as one of a range of HIV counselling and testing approaches. Although this model of HIV testing is seen as a new way of reaching under-tested populations, no studies have been conducted on offering self-testing to children. HIV self-test kits are now available in South Africa and are sold without the purchaser testing to be a certain age. Nevertheless, all HIV testing in children must comply with the norms set out in the Children’s Act (2005). Here we explore whether offering self-testing to adolescents would be lawful, by outlining the legal issues that must be dealt with and applying them to self-HIV testing. We conclude that, although children aged 12 years could consent to such a test, there would be two potential obstacles. First, it would have to be shown that using the test is in their best interests. This may be difficult given the potential negative consequences that could flow from testing without support and the availability of other testing services. Second, there would need to be a way for children to access pre and post-test counselling or they would have to be advised that they will be expressly forbidden to test. The tests are more likely to be lawful for a small subset of older children (15) as it assists them with HIV prevention strategies. If they will be able to occur (informed, consensual, and supported, even though they have tested outside of a health facility and HCT psychosocial support services are made available to them via the internet or cell phones).

SAHIVSOC 2014
Key points

- The FDA-approved OraQuick In-Home HIV Test is the only HIVST kit that meets international standards. Other less rigorously evaluated diagnostics, however, are available over-the-counter or through

- With current tests, user errors are very common. Key challenges included: the lack of integrated test components, poor labeling and unclear instructions on how to perform the test and how to interpret results.

- Ethically:
  - HIV testing, has results that are arguably no more life-changing than those of other diseases and conditions, such as diabetes and pregnancy, for which self-testing is readily available and less rigorously evaluated.
  - Challenges - scaling-up testing where treatment is unavailable, increasing user autonomy without support, and increasing potential risk for coercive testing, inter-partner violence, and psycho-social distress, especially in settings with pre-existing violence and among key populations who fear accessing HIV services. Moreover, HIVST will also impact legal policies that criminalize the transmission of HIV and could alter who incurs responsibility for partner-notification and linkage to HIV services.
“Despite the limitations, this review found very little evidence of any harm occurring in the practice of self-testing. Based on these findings, we recommend that HIV self-testing not be restricted based on fears of harm, but rather that as self-testing is expanded, researchers and policy makers pay particular attention to monitoring and measuring for unintended harm.”
Recommendations

“To fully maximize the opportunity HIVST presents, the public health community can support the current momentum by ensuring that:

- post-market surveillance systems are developed,
- estimates of the market size and cost-effectiveness of HIVST are enhanced,
- policy and regulatory systems to ensure the quality of available HIVST kits are developed,
- systems to monitor and report social harms, and track and identify how people who self-test are linked to prevention, care and treatment services are developed, and
- Innovative methods and technologies are leveraged, such as mHealth and eHealth interventions.”