

From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing

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Since recognition of the first cases in 1981, AIDS has been handled differently from other infectious diseases. Recently, therapeutic interventions that influence the clinical course and perinatal transmission of human immunodeficiency virus have become available.¹⁻³ In this paper we argue that earlier and more widespread diagnosis of HIV infection will be required for these interventions to fulfil their potential.

Origins and nature of HIV/AIDS exceptionalism

At the start of the epidemics in the United States and the United Kingdom, men who have sex with men argued when HIV/AIDS was first recognised—with the support of civil liberties groups, physicians, public health officials and others—for policies that differed from a traditional infectious disease control approach.³⁻⁶ This strategy has previously been termed “HIV/AIDS exceptionalism.”³ Clinical confidentiality and anonymised surveillance systems were emphasised, and informed consent was strengthened. The use of HIV antibody tests, when they became available, was restricted in a way not seen previously for other diagnostic investigations. This initial response, based on concerns about abuses of civil rights, was influenced by the vocal involvement of members of affected communities in the science and politics of HIV/AIDS (AIDS activism).

Exceptionalism initially had a limited effect on clinical care because treatment had only a modest influence on prognosis. The issue of generalised antenatal testing in women retained a low profile because women accounted for a minority of people in industrialised countries infected with HIV. Concerns about discrimination and compulsory testing dominated debate at a time when the only measures to prevent transmission to infants were termination of pregnancy or avoidance of breast feeding.

Normalisation then refers to treating HIV/AIDS more like other infectious diseases for which early diagnosis is essential for appropriate therapeutic and preventive measures, within the requirements of informed consent and respect for confidentiality.

Recent advances in HIV/AIDS

A number of recent scientific advances have major implications for practice.^{2 7-9} Plasma concentrations of

Summary points

Around half of prevalent HIV infections in England and Wales remain undiagnosed; in London less than 20% of HIV infected pregnant women are diagnosed by the time they give birth

More effective interventions influencing the clinical course and perinatal transmission of HIV have recently become available

People infected with HIV must be diagnosed early to translate therapeutic advances into public health benefit

HIV/AIDS must be normalised. All doctors should be competent in offering voluntary HIV testing and diagnosis

In areas where HIV prevalence is high, systematic voluntary HIV testing should be strengthened in hospital patients and in the traditional settings of sexually transmitted diseases clinics; testing should be offered universally as part of routine antenatal care

HIV-1 RNA are now measured as a predictor of outcome, for determining initiation of antiretroviral therapy, and for monitoring response.⁹⁻¹¹ Combination antiretroviral therapy, including potent newer drugs such as the protease inhibitors, has been shown to be superior to monotherapy and to improve survival.¹²⁻¹⁴ Treatment in acute HIV infection has been shown to improve prognosis.¹⁵ Although uncertainty about the duration of these effects remains, treatment advances are thought to be the major reason for the 6% reduction in the incidence of opportunistic infections associated with HIV/AIDS in the United States and 23% reduction in mortality from AIDS in 1996 compared with 1995.¹⁶ Similar changes are occurring in the United Kingdom.¹⁷ These observations emphasise the importance of early diagnosis of HIV infection for initiation of appropriate biomedical interventions.

The ACTG 076 study showed that zidovudine given to pregnant women and their newborn infants substantially reduces the risk of perinatal HIV transmission.¹⁸ Avoidance of breast feeding by women

aware of their HIV infection is also important. Gibb et al have shown that a substantial proportion of perinatally acquired HIV infections in London could have been prevented if infected women had been identified and available interventions had been offered.¹⁹

Where is HIV infection diagnosed?

Facilities have long been available for confidential (named) counselling and testing, and sites such as sexually transmitted diseases clinics routinely offer HIV tests to their patients. Early advice on HIV testing emphasised the disadvantages and uncertainties associated with a positive test, including potential human rights abuses and inability to obtain life insurance.²⁰ Nevertheless, each year over 2 million named HIV antibody tests are conducted in the United Kingdom as part of blood donor screening, with only written information made available before testing (National Blood Authority/Public Health Laboratory Service, unpublished data).

A recent audit of named HIV tests at a London teaching hospital showed that 61% of requests were from the genitourinary medicine clinic, 12% from the fertility clinic, and 6% from the drug dependency unit, the remainder being spread over a dozen other services.²¹ Few HIV tests are performed in London outside of selected specialties, antenatal testing is very limited, and internal medicine services test hardly any patients.

Improving the detection of undiagnosed HIV infections

The prevalence of HIV infection is monitored in many countries through unlinked anonymous testing, whereby residues of specimens collected for other purposes are tested for HIV infection after removal of personal identifiers.²² Efforts are required to increase uptake of HIV testing among populations shown by such serosurveillance to be at high risk, such as injecting drug users and men who have sex with men, if they are to benefit maximally from therapeutic advances. Care will be needed to ensure equal access across subgroups, including members of ethnic minorities at risk.²³ Pregnant women and hospitalised patients are two accessible groups in whom access to biomedical interventions could be greatly improved.

Pregnant women

Department of Health guidelines were published in 1994 to promote voluntary HIV testing for pregnant women.^{24 25} In 1995, the available evidence shows that in London less than 20% of pregnant, HIV infected women were diagnosed by the time of birth of their infants,²⁶ implying that until now, mother to child transmission has not been influenced by the results of the ACTG 076 study. However, uptake of appropriate interventions is high when women receive a diagnosis of HIV infection,¹⁹ and women who know their HIV status seem to change their reproductive choices.²⁷

A major factor influencing rates of testing is the attitude of attending midwives and obstetricians.²⁸ Reticence to advocate testing is often related to concerns about involuntary testing, stigmatisation, and discrimination against women seen to be at high risk,

since the highest prevalence of HIV infection is in women of African origin. Midwives and obstetricians urgently need to be trained in policies and practice concerning HIV prevention.

The poor record in the United Kingdom of prevention of mother to child transmission contrasts with achievements in France and the United States, where new infections in infants have been reduced significantly.^{29 30} Since effective interventions now exist, failure to offer voluntary HIV testing to pregnant women and appropriate interventions for those infected should be considered negligent.

Hospitalised patients

Unlinked anonymous testing of hospital attenders having full blood counts performed in four London hospitals in 1995 revealed an overall prevalence of HIV infection of 1.7% in men and 0.6% in women aged 16-49.²² About half were likely to represent unrecognised infections.

A study in the United States showed a range of HIV seroprevalence of 0.2-14.2% in sentinel hospitals and documented that almost two thirds of HIV infected patients presented for conditions not obviously related to their retroviral infection.³¹ The authors recommended offering HIV testing to all patients aged 15-54 in hospitals that have a diagnostic rate of AIDS of at least 1/1000 admissions, estimating this could have detected about 9% of the estimated national total.

Other settings

The finding of HIV infection prevalence of up to 1% of men in some populations of general practice patients³² suggests general practice is another area where increased HIV testing may be appropriate. Some urban practices care for a disproportionate number of people from groups with high rates of HIV infection, such as people from sub-Saharan Africa, injecting drug users, or men who have sex with men. Facilities for testing in traditional settings such as sexually transmitted diseases clinics could be strengthened and made more convenient to users—by offering same day testing, for example.³²

Home testing

Access to HIV testing in the United Kingdom has been carefully controlled by the official health services, but internationally this may be changing.³³ Home testing (but not self testing) has now been licensed in the United States, and the technology exists to develop self testing independent of counselling services.³⁴ While caution is clearly required, the reticence around the concept of self testing contrasts with modern approaches to self diagnosis or screening for other conditions such as breast self examination, home pregnancy testing, and melanoma awareness.

Public health implications of increased HIV testing

Encouraging more widespread HIV testing is consistent with the traditional public health approach of case identification, treatment, and promotion of strategies to prevent further transmission. Few experimental

studies give insight into the behavioural benefits of HIV testing.³⁵ Observational studies suggest that people with positive test results can change towards safer sexual behaviour,^{36, 37} and there is a widespread opinion that insufficient attention has been given to interventions aimed at promoting safer behaviour by people infected with HIV. A potential negative consequence of recent clinical advances is the perception by people at risk that HIV/AIDS is now treatable, or that antiretroviral therapy might reduce infectiousness, so that prevention practices can be relaxed. The impact of new therapies and testing strategies on behaviours should continue to be monitored.

Increased HIV testing will require clinicians in all disciplines to be familiar with modern HIV/AIDS medicine and to have basic skills in pretest discussion and obtaining informed consent for testing.³⁸ The financial implications of earlier diagnosis of people infected with HIV, who may require antiretroviral and prophylactic treatment as well as regular monitoring of CD4 lymphocyte counts and viral load, will require evaluation. Increased survival will result in an increase in the prevalence of HIV/AIDS, with important implications for cost and prevention.

Benefits of HIV/AIDS exceptionalism

Though we believe that more extensive HIV testing is necessary, we acknowledge that the exceptional status of HIV/AIDS has enhanced communication between doctors and patients and has made medicine less formal. Autonomy has been strengthened and patients have become more involved in decisions about their own care. Individuality has been more readily acknowledged, respect for informed consent and confidentiality has increased, and patient advocacy has emerged as a force for change.

Negative consequences that may result from people discovering their positive HIV status include psychological disturbance, rejection, stigmatisation, and social as well as financial discrimination. HIV infected women in some settings are at increased risk of domestic violence.³⁹ Most of the adverse effects of testing result from stigmatisation and discrimination, and strong measures to combat these must accompany efforts to normalise HIV/AIDS.

Conclusions

Although more cases of HIV infection were diagnosed in England and Wales in 1996 than in any previous year, probably little more than half of all prevalent HIV infections have been diagnosed. The proportion diagnosed is lowest among people infected heterosexually (A Nicoll, personal communication). To translate research advances into public health benefit will require people who are infected to be diagnosed early. To achieve this, HIV/AIDS needs to be normalised and its diagnosis considered a task for all medical practitioners, even if subsequent management needs to be supervised by specialists.

Two obvious situations for routine offering of voluntary HIV tests are in pregnancy and in patients undergoing hospital treatment. There is also a role for more widespread HIV testing by general practitioners, perhaps in a targeted fashion, and testing facilities in

sexually transmitted diseases clinics should be strengthened. Offering HIV testing to pregnant women, as part of routine antenatal care, should be universal. This will have greatest impact in areas where HIV is most prevalent, as determined by surveillance.²² Public health campaigns should consider encouraging awareness of individual HIV serostatus, especially for people from groups with high prevalence of HIV.

The exceptional status of HIV infection and AIDS usefully drew attention to neglected issues concerning individual rights in the context of medicine, including the requirement for informed consent and confidentiality. These rights must be guaranteed before individuals are tested for HIV, and they deserve strengthening in other areas of medicine. However, recent advances demand reassessment of older norms concerning HIV testing; without this, what once was protection of individual rights may now represent negligent practice and missed opportunities for prevention.

This paper was stimulated by observation by KMDDeC of the case of a 38 year old, white, married, diabetic, heterosexual man who presented with *Pneumocystis carinii* pneumonia (CD4 lymphocyte count $10 \times 10^6/l$) after more than 12 months of undiagnosed symptoms suggestive of HIV disease (weight loss, fever, sweats). HIV testing earlier in his course might have prevented his near fatal presentation and progression to end stage immune deficiency.

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HIV testing and HIV prevention in Sweden

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HIV testing is central to Sweden's programme of preventing the spread of HIV infection. It has been widely promoted and encouraged on the grounds that once HIV infected people are aware of their serostatus and receive appropriate counselling, they will take the necessary steps to protect their partners.¹ This faith in the inclination of citizens to protect one another is underpinned by a legal structure which bestows great powers of control on public health authorities. Many Swedes argue that the Communicable Diseases Act is superfluous and even harmful to HIV prevention efforts, but others regard it as essential to the country's HIV prevention and control programme.

HIV and AIDS in Sweden

That the promotion of HIV testing in Sweden is effective is reflected in the fact that the country has one of the highest rates of HIV testing per capita in Europe. By 1996, 9.5 million tests had been carried out among Sweden's population of 8.5 million (Swedish Institute for Infectious Disease Control, unpublished data). As of 1992, 1 in 100 000 blood donors had tested positive, compared with 1 in 10 000 pregnant women, 1-2 per 1000 patients with sexually transmitted diseases, and 1 in 1000 among the remaining population.²

By December 1996 Sweden had reported 1477 cases of AIDS and 4407 cases of HIV infection. Approximately 60% of the cases of HIV infection had been reported in Stockholm county, where the main route of transmission has been homosexual sex (table). Most cases of HIV infection that have been transmitted through homosexual sex and through intravenous drug use have been in Swedes, but most cases of heterosexually transmitted HIV infection have been reported among people born outside Sweden.³

Summary points

Preventing the spread of HIV infection in Sweden depends on identifying HIV positive people through mass HIV testing and counselling

It is assumed that once HIV infected people are aware of their serostatus they take whatever steps are necessary to prevent transmission of the virus

A widely held belief in Sweden is that Swedes place a high value on the collective good as opposed to purely individual freedoms

The Communicable Diseases Act provides public health authorities with huge powers over HIV infected people and the doctors who treat them

Swedish opinion is divided over the utility of this act in terms of HIV prevention, and the need for legal reform is being considered

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Role of HIV testing in HIV prevention

In Britain the HIV test is regarded chiefly as a diagnostic tool, and relatively little emphasis is placed on the social, or preventive, role of HIV testing. By contrast, Sweden's health authorities believe that "one of the most important strategies to stem the spread of HIV is to encourage the screening of all those who are at risk of being infected"⁴ because an individual who is aware of his or her infection makes behavioural changes that lessen the risk of transmitting the infection further.⁵⁻⁷

It is notoriously difficult empirically to verify assumptions such as this. The Swedish Institute for