

1

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SCREENING FOR
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ETHICAL ISSUES OF
ROUTINE UNIVERSAL SCREENING

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Few diseases have raised as many ethical questions as AIDS and HIV infection. One of these questions concerns the use of blood tests to identify individuals infected with HIV. Because there is no known cure for AIDS, most efforts today aim at reducing the number of cases through prevention of transmission. This fact sparked the debate over identifying HIV carriers. Fear of transmission throughout much of the population has led many to call for a universal routine screening to identify people who are seropositive for HIV and who therefore could transmit the virus to others.

In this short presentation, the ethical issue concerning systematic screening of an entire population is purposely ignored because such a screening programme is hardly feasible and the costs of the operation are very high. I think that it is more appropriate to focus on the following two main issues: (a) an explanation of the set of general ethical guidelines that serve as a basis for all screening programmes, whether voluntary or mandatory; and (b) the application of these ethical principles to the issue of routine universal screening to specific groups in a hospital setting.

Principles and Prerequisites for Evaluating a Screening Programme

To evaluate the ethical acceptability of a proposed screening programme, six criteria are usually recommended:

1. The purpose of the screening must be ethically acceptable.

There is at present one acceptable purpose for screening to stop the spread of an infectious disease. This purpose draws on the principle of beneficence which is the most fundamental principle in the Hippocratic tradition in

medical ethics. The principle of beneficence which for many centuries inspired the medical profession asserts an obligation to do good and to actively prevent and remove harms from patients and the community. The constant effort of the medical profession to relieve suffering, to meet human needs, and to enhance the human condition are rooted in this value.

Accordingly, the principle of beneficence asserts that it is the duty of the medical profession to protect the welfare of those who might become infected with a disease. Moreover, medical tests and the use of public health facilities should aim to protect the health of the community. If a therapy or vaccine becomes available to cure a particular infectious disease, a screening programme would always be justified in order to identify patients so that they may be treated and at the same time cease to be a risk of infection to others.

2. High-quality laboratory services must be used.

Given the importance of interpreting not just one but a series of tests to arrive at a confirmed positive result, the availability of highly qualified technicians and laboratory services is essential. Beneficence requires that persons not be subject to any risk - whether social, psychological, or medical - if the information about them to be generated in screening does not meet the current standard levels of accuracy.

3. Individuals must be notified that screening will take place.

Respect for persons requires that individuals be notified that they are or may be the subjects of screening. In some cases individuals may choose not to participate in the activity for which screening is required. In other cases, they may not have that option; but they should, nevertheless, be notified to protect their autonomy. Physicians who contemplate testing an individual on the basis of membership in a risk group should notify the person and should seek consent.

4. Individuals who are screened have a right to be informed about the results.

There is no ethical justification for withholding test results. Certainly that information may be profoundly disturbing - not just to the individual but to the health

care provider who has to convey it - but both respect for persons and beneficence support notification. The most important potential benefit of the knowledge of a positive test result to an individual is the motivation to change behaviour that puts others at risk or to take the necessary precautions.

5. Sensitive and support counselling programmes must be available before and after screening to interpret the results, whether they are positive or negative.

Individuals should be counselled about positive and negative results, and informed about the availability of future counselling. A confirmed positive test result should not be conveyed by letter. It should be provided by personal contact in the context of competent counselling services.

6. The confidentiality of screened individuals must be protected.

Respect for the privacy of those who undergo therapeutic and diagnostic procedures demands that the results of such procedures be kept confidential. In the case of HIV antibody testing, where the inadvertent disclosure of positive test results could have disastrous social consequences for individuals, the importance of preserving confidentiality is especially critical. However, there are a few circumstances in which public health reasons could provide a justification for the breach of confidentiality. For example, if it were known that a seropositive individual had recently donated blood, notifying the blood collection agency would be appropriate on grounds of benefiting blood recipients. However, that agency would then have the obligation to protect the confidentiality of the information received.

Universal Routine Screening

After establishing an ethical framework for the evaluation of all screening programmes, I now turn to the specific application of these principles and prerequisites to the question of routine universal screening. In a hospital setting the issue of routine universal screening is particularly faced by gynaecologists during antenatal blood testing and by physicians before surgical operations.

Universal routine screening can be ethically justified on the basis of beneficence when (i) a therapeutic intervention is available or (ii) when an infectious state puts others at risk merely by casual contact. However, neither is the case with AIDS. Thus, there is no demonstrable public health benefit that justifies mandatory universal routine screening, given the invasion of privacy involved.

Screening for AIDS cannot be compared with screening for hepatitis or for sexually transmissible disease. The fact that a number of sexually transmissible disease can be cured by a specific treatment justifies voluntary routine screening. Though there is no specific treatment for hepatitis, the risks of infection are controlled by vaccination. Thus routine screening can be justified in order to protect those who might be in contact with the infected person. However the case of AIDS is quite different because there is no known treatment or vaccine. If an effective treatment or vaccine would be discovered for AIDS, the situation would be different.

The danger to health professionals - those who come into intimate contact with blood or body fluids - is real. A small number of health professionals have become infected by exposure to infected blood in the course of their work. As far as I know, 22 cases have been reported. At the moment, this number is not large enough to justify either involuntary routine screening or to refuse to treat the patient who rejects testing. However, should this number increase, then arguments for involuntary testing could gain strength. The best solution to this problem is that the health professional would take all the necessary precautions with all patients.

Respect for the right to physical integrity and the principle of medical ethics requires that no person is subjected to the taking of blood without his or her prior informed consent. The taking of blood for HIV testing does not constitute a simple routine procedure. Implied consent cannot therefore be assumed. The physician is morally obliged to advise the patient of the value of testing. Since the patient has the right to self-determination, which includes the right to refuse the possibility of treatment, informed consent should always be sought.

This ethical standpoint is endorsed by Recommendation no. R (89) 14 of the Council of Europe adopted by the Committee of Ministers on October 24th 1989. It states that in the light of present knowledge and in the absence of curative treatment, any form of systematic screening is unethical and contrary to the rights of the individuals, if carried out automatically without informed consent and without counselling, because it overrides the principles of autonomy and physical integrity, and affects the privacy of the individual.

Experience indicates that universal routine screening policies, when not based on informed consent, are likely to be detrimental to HIV prevention efforts since those people most at risk of infection are likely to avoid contact with health authorities in order to escape identification and compulsory testing. Thus, the obligation of states to protect the public health requires the avoidance of universal routine screening measures.

There are, however, limited circumstances in which universal routine screening is appropriate. The routine screening of all donated blood and blood products has aroused virtually no opposition because everyone has an interest in a blood supply that is free of HIV. For similar reasons there should be universal routine screening of cells, semen and organ donations, in compliance with the usual strict requirement of informed consent and regulation for confidentiality of data. The recommendations adopted by the Committee of Ministers of the Council of Europe specifically refer to this point. In blood, semen or live organ donations, individuals can avoid screening only by avoiding the activity.

Routine universal screening without consent is ethically justified when it is carried out for the purpose of generating epidemiological data. Such screening programmes should be based on unlinked anonymous testing in order to protect the confidentiality of the individual's test result. Neither the clinician or the patient is informed of the result of the test. The results of these surveys are solely used to provide health service planning information. Where an individual has consented to the taking of a sample of his or her

blood for purposes other than HIV testing, the potential to be gained from the collection of epidemiological data might justify HIV-antibody testing of the stored blood. However, stored blood should not be tested without the expressed consent of the donor unless either his or her identity cannot be traced, or strict confidentiality can be guaranteed.

Alternatives to Universal Routine Screening: The Promise of Voluntary Testing

Those at high risk for developing AIDS have a moral obligation to take all possible steps to prevent harm to others, including taking the antibody test. Universal routine screening without an explicit consent would violate norms of beneficence and respect for persons and might drive the HIV infected persons underground.

Given the risks associated with AIDS and the uncertainty about what will in fact modify high-risk behaviour, there is a strong community interest in encouraging voluntary testing. In one of its reports the WHO insists that facilities for voluntary testing should be widely available, accompanied by counselling before and after screening. Public health authorities should encourage the use of such tests, and be taken anonymously or with strictly confidentiality protection.

Conclusion

I believe that one of the most effective means for stopping the spread of HIV infection lies in the voluntary cooperation of those at high risk - their willingness to undergo testing and to alter their personal behaviour and goals in the interests of the community.