

# CONSENT, WITH PARTICULAR REFERENCE TO HIV AND AIDS

*According to Volschenk, 'consent is the most important principle which the doctor will encounter in his medical practice'.*

## G J KNOBEL

*MB ChB, DipForMed, MMed (Anat Path)  
FForPath*

**Retired Chief Specialist/Emeritus  
Professor**

*Department of Forensic Medicine  
University of Cape Town*

*Professor Deon Knobel has been actively interested in medicolegal, ethical and human rights aspects of AIDS and HIV infection and is the author of many publications in the medical and lay press. He has also organised numerous awareness and educational programmes on AIDS for health care workers, students and the general public, including a highly successful summer school course at UCT in 1991. He has*

*attended 7 international AIDS conferences since 1989, and presented at 4 of those. He serves on AIDS Advisory Committees of UCT, at Groote Schuur Hospital and the CPA Branch of Hospital Services, and has been an invited participant at a number of policy workshops arranged by the AIDS Unit of the Department of National Health and Population Development.*

The general principles of consent and the special situation surrounding consent and HIV/AIDS have been covered in detail in an earlier edition of *CME* (February 1992, No. 10, Vol. 2).

The following questions are relevant to consent to medical and surgical examination and treatment:

- What is consent and when does it become informed and valid?
- Who may give informed consent?
- What age requirements are necessary for consent to be legally valid?
- Why is informed consent a requirement?
- When should informed consent be obtained?
- Who should obtain informed consent?
- What information should be given in order to obtain informed consent?

## WHAT IS VALID CONSENT?

For consent to be legally valid the person giving such consent must be legally competent to do so, must clearly understand the implications of the consent and must have adequate information to make an informed decision, without coercion or threat.

For example, a patient was informed by a surgeon that he needed a particular procedure, but given little further information. The surgeon told the patient that he would return to discuss the procedure and deal with the consent

form. However, the patient was in theatre waiting to undergo the procedure before a nurse handed a consent form to him. He refused to sign and when the surgeon arrived, he was told that unless he consented to the procedure, his application for a medical board would fail. This was clearly grossly unethical, if not illegal.

The degree to which the doctor should explain risks and possible detrimental effects of tests and treatment remains a dilemma. Morrison maintains that 'many patients, if not all, do actually trust their doctors. They come to them for expert advice and are prepared to accept the judgement made by the doctor who will have balanced the various risks . . . Of course we should try to explain the treatment (tests) we are offering or advising.'

Gostin, discussing the pros and cons of routine HIV screening of all patients, warns that the doctrine of informed consent is based upon the principle of patient autonomy and not paternalism. The patient requires all relevant information regarding a procedure (test) in order to assess its value and whether adverse consequences would be intolerable for the reasonable, prudent patient. The test of 'materiality' should be applied, namely whether a reasonable person would have consented to the test or procedure based on the information supplied by the clinician. The doctor, even if he or she may consider the probability of an adverse result to be slight, may therefore not withhold information if it is relevant to the patient's ability to make an informed decision.

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**CONSENT AND HIV/AIDS\***

With regard to HIV infection and AIDS, the same legal and ethical principles as for any other medical examination and/or treatment, as defined before the advent of AIDS, would apply. However, it is unfortunately true that patients have not always been tested for HIV status for their own benefit. Real and perceived risks to health care workers, the temptation to take (extra) precautions apart from internationally recommended universal precautions, and the fact that some health care workers refuse to treat HIV-infected persons have led to people questioning the need for informed consent before such testing. However, an HIV-positive diagnosis carries serious implications. Should an HIV test be performed without informed consent and found to be positive, the results can be devastating.

\* In view of the risk of transmission of HIV and other infectious diseases, the Department of Health of the Government of the Western Cape Province issued an instruction in June 2003 to all hospitals under its control that explicit informed consent should be obtained from patients or the parents or guardians of minors before transfusion of blood products.

While consent is essential to HIV testing, there are many situations in which doctors and other health care professionals still find it difficult to make decisions about HIV testing. This is best illustrated with some cases.

**Case 1: HIV testing without consent or pre-test counselling**

Any doctor taking blood for an HIV test is obliged to inform the person of the consequences of a positive test and to ensure that the result is confidential. Dorrington (I Dorrington. Living with AIDS. Radio South Africa Documentary: 1 December 1991) lost his employment as a result of a breach of confidentiality when an HIV test for insurance was found to be positive.

It is strongly recommended that, when a person is found to be HIV-positive as a result of insurance testing, the result is relayed by a doctor and that the person has the option of withdrawing the application for insurance (or employment) without breach of confidentiality. The Medical Protection Society clearly states that if a doctor tests a patient without the patient's consent, and the patient suffers loss of insurance or employment as a result of a positive test, the doctor can be held liable for such loss.

**Case 2: HIV testing after death**

The driver of a car that was involved in a serious accident sustained major lacerations to his hands. While the driver was still at the wheel of the car, the body of a pedestrian was thrown through the windscreen and bled profusely over the driver's open wounds. The body of the pedestrian was admitted to a police mortuary simultaneously with 2 other bodies from unrelated accidents on the same night from the same public road. The identities of all 3 bodies were unknown and they received mortuary numbers close to one another. The driver of the car was concerned about the HIV status of the body that had come through his windscreen and

asked that blood be taken from all 3 bodies, for an eventual HIV test on the correct body.

Ethically, this presents problems. In this case the author consulted the head of the department of forensic medicine at the hospital concerned. The conclusion was that if the identities of the bodies were known, then the relatives should be consulted. As the identities were unknown the blood was taken for later HIV testing of the specimen identified to belong to the body involved in the accident. The specimen unfortunately turned out to be unsuitable for testing.

A similar dilemma exists in cases where emergency workers are exposed to the blood of an unconscious patient who is not able to give consent for HIV testing. In terms of the National Health Act relatives, including a partner, may now, as for any medical emergency, give or withhold consent. If patients are conscious, their consent for HIV testing should be sought and they should be asked if they would like to know the result. If the patients refuse consent for HIV testing, the suggestion is that they are informed that their blood will be tested, and that the result will be withheld from the patient concerned and all records of the result destroyed.

**Case 3: Routine HIV testing as part of employment policy**

An employee at a state institution where there is regular exposure to foreign blood and other body fluids was tested for HIV as part of a policy that required routine testing every 6 months. The results were strongly positive, with the predictable highly emotional response from the employee, who became suicidal. An immediate confirmatory test was advised, which was negative. The original specimen of blood from the private laboratory was submitted to an academic institution for PCR, which was again strongly positive. The patient's blood was matched with the original specimen and blood group and DNA gave a perfect match. Two years later, the

patient still tests HIV-negative. No scientific explanation could ever be obtained for the strong false positive result.

Many legal and ethical issues were raised by this particular employment policy of routine testing. There was no informed consent obtained prior to testing. Employees gathered in a group to wait for the nurse to take specimens. The result was then telephoned to a clerk, immediately breaching confidentiality. A positive test was not automatically followed up with a confirmatory test as is internationally recommended. No post-test counselling was available. The policy of routine testing has no basis in science if universal precautions are used when handling body fluids. This same institution had a policy of post-exposure prophylaxis in force for some years before this incident. In spite of this, the routine testing policy remained in force until this particular incident.

**Case 4: Testing a child for HIV to decide on the level of treatment**

In a study of the effects of the lack of training in bereavement counselling an intern reported that at the paediatric unit in which she worked, seriously ill children brought into the emergency unit after hours were given a rapid HIV test, with no counselling being offered to the parents. Children who test positive are not sent to the paediatric intensive care unit, the parents are not told of the result of the HIV test and are also not told why their child is not receiving further treatment.

This is clearly not only illegal, but unethical and immoral. Sadly, this is the reality in many hospitals around the country.

**Case 5: Use of HIV-positive children for publicity**

A day mother, not related to the child, took a small child with HIV infection to a day clinic. A visiting celebrity donor was photographed with the child, probably more for publicity for the celebrity than for the benefit of the child. Relatives of the child saw the picture in a newspaper and reacted with outrage, with disastrous consequences for the mother, whose status until then had been unknown to her family.

In the World AIDS Day 2005 edition of *The Citizen*, Ryk Neethling poses in a swimming pool with a clearly recognisable HIV-positive child from Nazareth House. This is unacceptable even though the publicity may be for the benefit of Nazareth House. This author has repeatedly expressed concern about the publication of recognisable pictures of minor children with a variety of conditions. A picture showing the back of the child's head would have been acceptable.

**Case 6: Lack of confidentiality in testing well-known people**

A well-known professional person consulted a general practitioner with a flu-like illness, severe generalised myalgia and a diffuse rash reminiscent of that seen in tick bite fever. Blood was submitted to a laboratory for HIV testing, without any attempt to protect the identity of the patient through encoding or a fictitious name on the forms. The subsequent positive result was sent via the dispatch desk of the laboratory to the receptionist of the practitioner. Confidentiality was immediately breached.

Every patient, irrespective of social class, standing or nature of illness has equal rights to privacy and confidentiality. In view of the stigma still attached to HIV infection and disease, doctors must protect the identity of patients at all costs and should develop a system of encoding for laboratory specimens. HIV test results, particularly if positive, should be sent as a confidential report directly to the doctor and not to the general office staff.

**CONCLUSION**

In the Bulletin of the HPCSA of October 2005 M Dada comments on ICD-10 coding and confidentiality: 'The health provider's ethical duty concerning confidentiality of medical information is clear and it is therefore advisable to obtain full and informed consent from the patient...prior to using and disclosing the ICD-10 codes to third parties such as medical schemes. The HPCSA is in ongoing debate... to harmonise rules concerning ICD-10 codes, so that... there is no inadvertent breach of the HPCSA ethical guidelines and possibly the patient's rights under the Bill of Rights in the Constitution of SA.'

In conclusion medical practitioners are reminded that detailed and strict HPCSA and SAMA guidelines exist regarding ethical treatment of all patients, with special attention given to patients with HIV/AIDS. Doctors are advised to adhere firmly to these guidelines and an appeal is made to all health care workers to act with integrity, discretion, understanding and knowledge, to ensure optimal and ethical care to all patients, including those infected with HIV.

**IN A NUTSHELL**

Legally valid consent must be given by a competent person, in possession of adequate information that allows him or her to make an informed decision, without coercion or threat.

A girl of 16 years and older may consent to sexual intercourse.

For medical examination and treatment a legally competent adult and any competent person over the age of 14 may give consent, without parental knowledge or assistance.

The Children's Bill, passed in Parliament on 30 November 2005, once promulgated into an Act, will reduce this minimum age to 12 years for medical treatment, including contraceptive medication requested by the child.

In certain emergency and life-threatening circumstances, where no family member or partner is available, the doctor uses discretion and treats an adult professionally and ethically as well as possible. It is advisable that the superintendent or officer specifically appointed for this purpose in a hospital should be informed of the situation and the treatment given and/or actions taken. Where permanent disability may result from non-treatment and parents refuse consent, the Minister of Health or a suitably delegated representative of the minister may give consent or a court order may be obtained.

For invasive and surgical procedures the minimum age of legal consent is 18 years.

It is ethically and morally important to respect and protect the privacy and confidentiality of a child, irrespective of age.

The same legal and ethical principles apply to HIV testing as apply to any other medical examination and/or treatment.

Large wall posters informing patients that HIV testing will be conducted routinely are not acceptable or adequate.

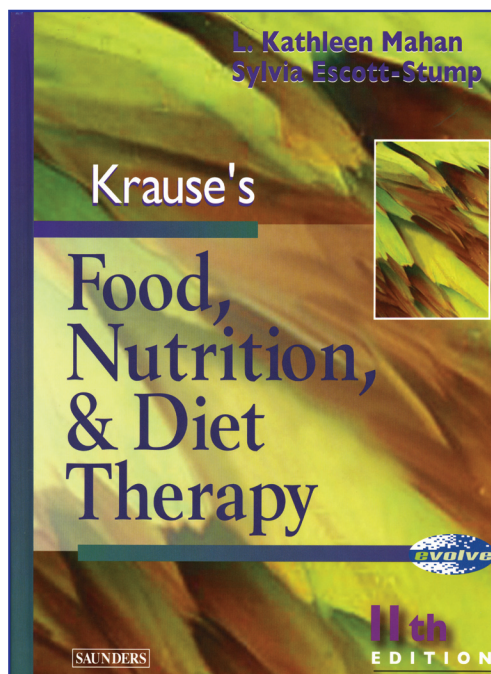
The treating doctor is responsible for obtaining consent and ensuring conformity to the ethical guidelines.

Oral consent, preferably with written documentation, is advisable; implied consent is not sufficient.

Emergency testing must be done in the best interest of and for the optimal treatment of the patient.

Testing in special circumstances, e.g. after needle-stick injuries, in pregnancy, after rape, pre-employment and before organ donation, carries special problems that must be fully considered before an HIV test is carried out.

There are advantages and disadvantages, to both the patient and the health care worker, of HIV testing and knowing the result of the test.



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