



CONSELHO NACIONAL DE ÉTICA PARA AS CIÊNCIAS DA VIDA

Report-Opinion 16/CNECV/96

On

The Obligatoriness of AIDS Tests

INTRODUCTION

The CNECV follows attentively the greater social problems, above all those most closely related to human life at the two-way frontier between science and ethics.

One of the most serious problems in the domain of Health is undoubtedly that of HIV-positivity and AIDS. The Acquired Immune Deficiency Syndrome has been striking an increasing number of citizens, whose family and friends are also affected, psychologically as well as socially. A situation of generalised anguish has actually been created, leading at times to marginalisation and even to types of social exclusion. Discrimination has struck health units, schools, business firms and the work place.

What is at stake, most certainly, is the possible conflict between individual rights and social rights, between public health and the rights of each citizen, when the latter is known to be HIV-positive or to be ill with AIDS.

International organisations, especially WHO (World Health Organisation), the European Parliament and even the UN (United Nations) have stood against such discriminations. The CNECV must also reflect on this theme and issue an opinion. This was not requested by any outside body: the Council itself deems it necessary to promote an ethical reflexion, directed as much to protecting the rights of AIDS patients and HIV-positive persons as to safeguarding the public health so indispensable to society, thus attempting to provide legislators with elements for the legal instruments they may yet produce, so that health rights may be guaranteed at all times.

The present opinion, since it focuses on the ethical appraisal of the obligatoriness of AIDS tests, has the objective, therefore, of affirming from an ethical perspective the right of HIV-positive persons and AIDS patients to non-exclusion from the working world and to a treatment analogous to that due to every citizen.



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REPORT

THE OBLIGATORINESS OF AIDS VIRUS TESTS

1. Prevention – its possibilities and limits

To speak about AIDS prevention entails proposing to the entire human community new forms of behaviour, running counter to habits, traditions and, sometimes, the very culture of the diverse groups involved. In the prevention of sexually transmissible diseases, citizens must be prepared to alter many forms of behaviour that might even constitute an assertion of their personality. During sexual initiation, in the easy-go-lucky behaviour of adolescence, in frequenting groups at risk, in a somewhat anarchic sexual lifestyle, situations may be encountered which propitiate HIV transmission. Prevention resides above all in proposing that behaviour be changed.

Such propositions are certainly related with an education oriented towards health, healthy lifestyles and daily hygiene, but also with the organisation of sexual life or the simple exercise of sexuality. In this context, the education of human sexuality has become urgent. It is no longer enough to impart information about the characteristics and mechanisms of sexuality. It is necessary to consider the close relationship between sexuality and emotional life, sexuality and life projects, sexuality and its expression of the communion of life and the continuation of life. Both the education of human sexuality and the health-oriented education presuppose an education oriented towards values: the meaning of life, the respect for others, the reason behind relationships, the construction of a joint project with the other, the dignity and the objectives of the body, education in responsible freedom, the whole dimension of loving.

In this perspective, as regards AIDS prevention, the WHO expressly refers:

- the value of monogamous relationships, “in permanence with a faithful, non-infected partner”;
- “abstinence from sexual intercourse”, when it lacks safety;
- reducing “(...) to a minimum the number of partners, avoiding as well sexual contact with prostitutes or any other person who has many sexual partners”;
- the use of a correctly applied preservative, from beginning to end of the intercourse “every time intercourse is maintained with persons who might be HIV infected”.

This recommendation by the WHO presumes the urgency of educating sexuality and affectivity, in the family, in the school, in health centres, in institutions often frequented.



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Changing personal and social behaviour does take up several generations, but each individual must impose upon him or herself a decisive pledge to cultivate essential values, which must include respect for the dignity of the person and the importance of solidarity with all persons.

2. Social Repercussions of AIDS

When, beginning in 1981, this disease became known, a panic situation was generated all over the world. There was the haunting fear that an entire society might be virtually infected, for every person could be infected; the risk groups especially, homosexuals and prostitutes, were strongly marginalised. Religious movements, taking the wrong advantage of a dramatic situation, claimed that each case was a punishment by God for the sin of sexuality, the origin of the scourge. Contagion and transmission were confused – though the disease is not contagious but simply transmissible. Collective fear was induced, leading to the systematic marginalisation of all HIV-infected persons. Such situations led to social exclusion of AIDS patients, many of whom were blamed for their sexual behaviour, stigmatised because they were considered a threat to public health, and practically abandoned to their fate for they unworthy of the solidarity of other citizens. It was thus that many AIDS patients lost their jobs, were ostracised by their friends and were even abandoned by their own families.

The association of AIDS with drug addiction, insofar as many drug addicts transmit the virus to others, worsened even further the social image of positive and afflicted individuals.

The social exclusion of HIV-positive persons and AIDS patients is a fact. Collective distrust leads to their being regarded with suspicion at school, in the work-place, at health units and in their social group. Cases are known where, on these grounds, children have not been admitted into school or allowed near other children, where workers have avoided colleagues who are fighting the affliction, where ailing persons have been confined, in some hospitals, within veritable ghettos, where friends have boycotted one of the group because he or she turned up with a “strange disease”. In such a social climate, business companies begin to feel the need to protect themselves. The presence of a person who is ill or even just positive upsets working relationships; there is diffidence, difficulty in interpersonal contact, fear of using the same spaces and the same objects. Entrepreneurial groups are afraid of being beset by problems that might disturb normal functioning of their units, their production and profitability, perhaps even damage their market image.

This collective attitude, especially as it appears in the entrepreneurial milieu, is due no doubt to a few factors which must be counteracted. It is due mostly



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to the manner in which information concerning this phenomenon has been divulged. Prevention was attempted by public scare, so that, instead of changing their own behaviour, several groups chose to protect themselves against contagion by excluding the sick, precisely at a time when they had most need of human support.

To make matters worse, it is difficult for many people to feel solidarity in these circumstances, to give support, to offer a roof and understand, to follow through the patients. There is fear of contracting the disease and, no matter how well people may know the manner of transmission, there will be hesitation anyway, because of the image created around this disease.

3. The juridical problem

Even though several international organisations — such as the WHO, the European Council, the European Parliament, even the UN — have already issued rather clear pronouncements on the social repercussions of the AIDS problem, Portuguese legislation still fails to provide for several situations.

The legislator must promote social guidelines of a didactic nature, standard codes of conduct and legal rulings determining preventive activity against the means of transmission of the disease, providing clear but non-alarmist information about risk situations, and denouncing situations of discrimination based on prejudice or ignorance.

All legislation to be introduced must in every case bear in mind the ethical principles of human dignity, Human Rights and other International Conventions, and above all the rulings already produced by the various international organisations on *de facto* situations.

As regards Human Rights, some fundamental principles are to be respected, already laid down in the Constitution of the Portuguese Republic, to wit:

- the Principles of equality and non-discrimination which constitute the essential nucleus of the rights of the person (Art. 13);
- the right to physical and moral integrity (Art. 25);
- the right to a personal identity, to one's good name and reputation, to one's image, to the reserve of the privacy of one's private and family life (Art. 26);
- the right to freedom and security (Art. 27);
- the right to the inviolability of the domicile, to keeping correspondence (Art. 34) and to the prohibition of the use by third parties of computerised records containing personal data (Art. 35);



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- and also the right to work, to education, to assistance, rights which are not forfeited or lost when one is afflicted by a disease (H.Rgts, Art.'s 23, 26 and 25).

AIDS raises some issues that must be provided for by the legislator with laws that are equitable and sufficiently up-to-date, such as:

- the possible conflict between the protection of the rights of the ill and the infected and the necessary protection of public health and the rights of other citizens;
- the issues relating to the confidentiality or publicity of the acts connected with detection, treatment, prevention, transmission and epidemiological follow-up;
- the process that will guarantee the right to treatment and at the same time ensure the duty of undergoing treatment and the prevention of contagion in the course thereof;
- the obligatoriness or non-obligatoriness of internment, isolation and compulsive treatment;
- the issues relating to voluntary, conscious and intentional transmission of the disease, and the penalties attending such behaviour;
- the affirmation of the social rights of those infected, especially as regards employment, education, social security and housing, and as regards situations of discrimination;
- obligatoriness or consent as regards the performance of individual tests and collective screening tests;
- and also the duties of all infected persons.

At present, on the basis of the laws in force and the several rulings and provisions contained in the Portuguese Constitution and in several orders by the Health Minister, as well those emanating from the European Council, the European Parliament and the WHO, the following does not appear to be licit:

- to promote compulsory collective screening tests to detect the disease, obligatory testing of suspected cases or the obligatory communication of individualised test results;
- to enforce or carry out compulsive analyses and treatments, coercive hospitalisation or isolation;
- to establish limits to the freedom of circulation of persons;
- to organise sterilisation programs for those affected by HIV;
- to impose legal or factual limits to work placements on the basis of infection, either subsequent to detection or as a pre-condition that it must not happen;
- to involve isolation situations for AIDS patients in prisons, for HIV-positive children at school, for workers at their work places.;



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- as regards insurance, to demand analyses for compulsory policies, or to impose clauses of dubious validity in some voluntary policies.

The legislator must also bear in mind the fact that the NGO's more closely concerned with these problems have stated their position clearly when they defined the rights of persons carrying HIV and AIDS. Among them, the following are noteworthy:

- no individual carrying HIV / AIDS may suffer damages or discrimination on the grounds of his/her health condition;
- carriers of the acquired immune deficiency syndrome virus have the right to preserve their image and anonymity.
- HIV / AIDS carriers have the right to work and to employment that are adequate to their state of health and compatible with the evolution of the disease;
- persons suffering from AIDS must be on equal par with other citizens as regards disability pensions, as from the moment their capacity to work becomes impaired;
- the same persons also have the right to housing, to family, social and school integration without discrimination, to freedom of movement and circulation.

4. The Ethical Horizon

When one discusses the obligatoriness of HIV or AIDS tests, what is at stake is not only a juridical problem but also, and especially, an ethical issue. Legality is not equivalent to ethical legitimacy. In the present case, it is important to emphasise that the obligatoriness of such tests is not ethically legitimate, because it does not respect the dignity and freedom of the human person with the rights and duties that attend them. A sick person, whoever he or she is, whatever the disease, is a person, the subject of rights and duties. A sick person's rights to work and to participation in economic and social life may not be restricted, just as no one may deny the sick person's right to life, to health, to privacy or to fundamental freedoms. A sick person is a person.

In the case of the HIV-positive and of AIDS patients, this concrete person bears specific characteristics that actually oblige society to dispense to him/her particular attention, given his/her vulnerable state. The patient, just because he/she is sick, does not cease to be a unitary being, a bio-psycho-social-cultural complex. The fact of being in the throes of biological difficulties, of going through a physical crisis, does not take away the patient's social and cultural rights, even when there is psychological impairment. On the other hand, this patient holds a history that must go on being written: he or she represents a culture, a family, a legal status, a



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professional avocation, a whole richness of life that must not be curtailed. A sick person is in a fragile state and must not be socially brutalised.

In this context, all discrimination is ethically reprehensible. Discrimination is all the more grievous the more it entails the diminishment of the right to privacy, of the confidentiality which behoves technicians, of the right to adequately provided assistance with personalised accompaniment by professionals, of the right to support in situations of poverty, when job loss renders more acute any situation of chronic want, of the right to re-socialisation, even at a terminal stage, when the conscience of being useful is an elementary contribution to the animic maintenance of the subsiding person.

It is part of ethical responsibility to provide the quality of life that concrete person is capable of. Such quality is not limited to material benefits, to physical beauty, to the access to consumer goods, to basic culture; such quality demands the interpersonal or even spiritual relationships which the social and professional milieu facilitates and heightens.

One may assert, therefore, that what is at stake is a fundamental ethical problem relating to the principles of equality between persons, without any discrimination; of the equality of opportunities in the face of specific situations; of access to the type of work for which one has a special vocation or preparation, of the guarantee of working conditions proportional to the worker's characteristics. Human Rights consecrate this fundamental principle in Article 23, when they affirm that every human being has the right to work, to the free choice of his/her work, to equitable and satisfactory working conditions and to protection against unemployment. Furthermore, it affirms that all have the right to equal pay for an equal job, without any form of discrimination.

The social exclusion to which many HIV-positive persons and AIDS patients are nevertheless subjected is due to wrong information being purveyed to the human community by the mass media about the manner in which prevention of the disease was carried out, due as well to sexual taboos that befall those considered to behave perversely, and, finally, due to fears by the population of a contagion that is actually impossible. A great deficit of ethical education must be acknowledged in this respect, leading the WHO to state, back in 1988, that

“There are no reasons of public health that justify isolation, quarantine, or any discriminatory measure, based only on the fact that a person is suspected of being, or known to be infected by the HIV virus. Such persons must remain integrated in society for as long as possible and they must, instead, be helped to assume responsibly the prevention of HIV transmission to others. The exclusion of persons suspected of being or



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known to be infected by HIV will be unjustified in terms of public health and will seriously damage educational and other efforts towards prevention of HIV propagation.”

The European Council said the same in 1987, in Recommendation 87, when it affirmed that *“discriminatory measures must not be introduced; in effect they have no justification, either from a scientific or from an ethical point of view.”*

The UN Human Rights Commission also considered, back in 1991, that: *“persons who are or might become infected must remain integrated for as long as possible in society, and must be given support in their responsibility to prevent transmission of the virus”. And, further on: “there are no reasons of public health to isolate infected persons and to discriminate them as regards housing, schooling, employment and other areas of social life.”*

5. AIDS virus tests and their obligatoriness

From what has been referred, the indiscriminate obligatoriness of AIDS virus tests is considered illegitimate, because it strikes at the privacy of persons, pronounces inhumane marginalisation, endangers individual freedom, engenders in society undesirable terrors, and renders impossible a responsible education directed towards social health and public health, of which all the foregoing are active factors. The universalisation of tests against people’s wills; screening tests of the population or of specific groups considered to be at risk, outside the will of the interested parties; sociological study surveys involving a geographically or socially defined group without the consent of the inquired; are therefore considered to be illegitimate from an ethical point of view.

Specific situations where obligatoriness of tests is tendentially more marked are the following:

- admittance of new workers at certain companies or business firms;
- contracting health insurance and life insurance or assurance;
- applying for bank loans.

Let us consider the first situation: admittance into a company or business firm. In all instances of the problem being evaluated, there was consensus over this situation. The European Council and the Ministers of Health of the EU Member States expressly declared on December 15th, 1988:



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“Workers afflicted by AIDS must be treated on an equal basis with workers afflicted by other serious diseases that affect the performance of their functions. When the physical condition of such workers deteriorates, it would be appropriate to arrange, if possible, some reorganisation of work locations and timetables, so as to allow them to carry on working for the longest possible period of time.”

Later, on December 22nd, 1989, in a new Resolution, they added:

“Any discrimination of persons afflicted by AIDS or by an HIV infection is a violation of Human Rights and is damaging to any efficacious policy of prevention, due to its effects of rejection and stigmatisation”. Furthermore, “It is meet that the utmost vigilance be exercised so as to fight against all forms of discrimination, especially in work contracts and in the work place, in schools, as well as in housing and health insurance.”

The European Council, in 1991, went as far as to recommend more than one type of vigilance, through its *Measures aimed at the non-discrimination of persons who are HIV infected and of persons who are close to them* –

- a regular analysis, at the level of the Community and with the co-operation of the member states, of situations that might imply discrimination;
- exchange of information about the measures taken by the member states to avoid discrimination;
- proposals, if necessary, of measures to be taken at Community level.

There are types of jobs, nevertheless, that by their nature justify the requirement of an HIV test: those that entail the manipulation of biological fluids that are to be administered to patients, and thus may induce contamination / transmission. Also, although being a donor is not a profession, it must be borne in mind that a blood donor or a sperm donor, as well as an organ donor must not be infected, whence the demand that they be tested is necessary. Beyond these cases, it would seem appropriate to apply the common sense consecrated in some guidelines by international organisations. The UN Social and Economic Council states: *“it may be legitimate to restrict individual freedom, if that should be necessary, in order to protect public well-being and health”*. This is no arbitrary discrimination, referring instead to a concrete situation of a specific activity. It cannot be considered discriminatory to enforce a screening test of all potential donors of tissues and organs for HIV, types 1 and 2, since donation is voluntary.

Regarding health and life insurance or assurance contracts, there is but one explicit reference to this situation, which appears in the December 89 Resolutions of the European Council, reading thus: *“It is meet that the*



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utmost vigilance should be exercised so as to fight against all forms of discrimination, (...) also in matters pertaining to housing and health insurance”.

From an ethical point of view, however, it does not appear to be illegitimate that insurance companies should demand a detailed report of the state of health of the person wishing to take out insurance, and it is incumbent on the normal client to provide the information requested, which conditions the amounts payable annually as premium of the contracted insurance. Without the truthful delivery of such information, the insurance contract would be vitiated. Here, it is the duty of the AIDS patient or HIV-positive person to inform the company correctly, so as to define the conditions of the contract that will be entered into. The contract is voluntary, with the HIV-infected person being able to give or refuse consent to analysis. An outright discrimination would be illicit. An identical situation prevails in the case of contracts sought with Banks, especially when they involve home buying loans under a system of immediate acquittal of debt upon death of the borrower. Here, too, refusal to grant the loan would be discriminatory, since the Bank always demands guarantees on the loan, either in terms of personal property or through guarantors who assume liability for a full settlement.

Some cases, however, merit special attention:

- medical doctors who are HIV-positive or ill with AIDS, given the high risk of transmitting to others the HIV viruses, through blood contact in the exercise of their speciality, are duty bound to renounce their speciality and limit themselves to less risk-prone activities;
- pregnant women should be advised, when there is reason that indicates it, to undergo HIV tests or even AIDS tests. There is universal and express agreement over the great interest of an early detection of HIV. This practise must actually be proposed to all pregnant women. Ethics Councils do not consider, however, that the tests need be compulsory, as part of the prenatal tests required by law. And this is so for two reasons: given the MD's liabilities and responsibilities regarding this preventive act and the difficulties inherent in his mission, the MD can lead the pregnant woman to accept the test without its becoming compulsory; on the other hand, one must bear in mind the misgivings pregnant women might experience in the face of an excessively rigid official position – they might refuse the test out of fear, induced by the obligation. Given that MD's can develop an efficacious prophylactic action, the institution of compulsory testing is not justified.;
- Finally, in the case of blood donors, of sperm donors and of tissue and organ donors, it is paramount that the tests should become



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compulsory. An person who is HIV-positive or ill with AIDS patient must not be a donor, in any of these cases.

Lisbon, January 17th, 1996

The Reporter,
Father Vítor **Feytor Pinto**

OPINION

A. Considering that the dignity and fundamental rights of the human person must always be respected, as laid down moreover in the Universal Declaration of Human Rights, which refers among others the right to health care (Art. 25), the right to work (Arts. 23 and 24), the right to participation (Art. 27) and the right to education (Art. 26);

B. Considering that persons testing positive to the AIDS virus as well as patients who manifest AIDS symptoms are persons in full right and that, for that very reason, they must not be subject to any discrimination, especially in matters relating to access to work and to such property or goods or services as are indispensable to a better quality of life;

C. Considering, however, that there are specific situations which, by their nature, merit special attention, since the health of third parties cannot be put at risk;

The National Council of Ethics for the Life Sciences issues the following opinion:

1. “ The obligatoriness of AIDS tests is, in principle, illegitimate because it runs counter to the fundamental right to privacy, it leads to inhumane discrimination of persons who are already in a state of great debility, it sacrifices the individual freedom of those citizens who are subjected to screening tests.

2. Testing for HIV 1 and HIV 2 as a condition of entrance into or permanence in a company, firm or in any work placement, are also in principle illegitimate, since these persons have the right to work for their self-realisation, they have the right to a salary, for their sustenance and maintenance, they have a right to professional advancement. Workers afflicted with AIDS must be treated on an equal basis with workers afflicted by other serious diseases that affect the performance of their functions. When the physical condition of such workers deteriorates, it would be appropriate to arrange, if possible, some



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reorganisation of work locations and timetables, so as to allow them to carry on working for the longest possible period of time.”

To elucidate these points we refer recommendations no. R(87)25 and R(89)14 of the European Council and the positions repeatedly assumed by the Health Ministers of the EU member states (15.05.87, 31.05.88, 15.12.88, 22.12.89 and 04.06.91).

3. All else notwithstanding, the CNECV recognises that for the practise of certain activities and in some limited situations, it should be possible to demand that the following persons be tested for AIDS:

- health professionals, who have direct contact with human organs or biological fluids;
- blood, sperm, tissue and organ donors.
- pregnant women, especially those whose clinical history (involving, for example prostitution or drug addiction) indicates high risk and the probability that they have been infected by the HIV virus.

4. The CNECV also considers that Insurance Companies have the right, in the case of life insurance or assurance contracts, to ask for a detailed report of their client’s state of health, and that the insured/assured person is bound to provide such information, on pain of vitiating the contract to be settled with that Company. Banks, too, when promoting loans that are immediately acquitted upon death of the client, have the right to receive faithful information, which, if not proffered, would vitiate the impending contract. The voluntariness of such contracts must be emphasised, which excludes coercion or the obligatoriness of having the test done.

5. Lastly, the CNECV finds that there is need for an action of information/ education that helps society, every person, every firm, every social structure, to consider the HIV-carrier and the AIDS patient as a human person, who has rights and duties, without any type of discrimination, with the social solidarity necessary at a difficult time, nevertheless demanding from him or her a great sense of personal responsibility in her or his private, professional and social life, so as not to become an agent of the transmission of this disease.

Lisbon, January 17th, 1996

The Reporter,

Father Vítor **Feytor Pinto**



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