

## Review Article

# Rights of Patients with HIV/AIDS: A Nursing Perspective

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**Abstract:** Introduction: Patient rights, as part of fundamental human rights, are protected and guaranteed both by international and national legislation. Individual rights of a patient are concerned with privacy and freedom protection and are also covered by urban and penal legislation provisions. With regard to health care, patient rights are closely connected to specific policies which include the administration and organisation of health care provision. Aim: The purpose of this position paper is to outline nursing deontology and patients' rights by discussing critically the case of confidentiality and consent of individuals with HIV/AIDS and related issues involved. Method: A critical debate is undertaken using resources from national and international literature. Results and Discussion: The results of this critical discussion paper are organized in six distinct sections which cover holistically the topic under debate, as follows: *Nurses and individuals; Nurse and practice; The current situation in Greece; Patient consent with HIV/AIDS; Medical confidentiality and HIV/AIDS and Ethical implications of HIV/AIDS patients in hospital*. This typology ensures that a true nursing perspective is presented regarding the rights of patients with HIV/AIDS both nationally and internationally. In this respect, it was deemed essential that results of this paper incorporate discussion as well as part of a critical comprehensive overview of a complex and challenging health care topic. Conclusions: The ethical, legal and moral dilemmas regarding patients with HIV/AIDS remain controversial and challenging. Respect for patients' confidentiality is a fundamental principle in medical ethics, and also a legal duty that health care providers owe to all their patients. However, the respect of absolute confidentiality has been subject of debate particularly in the case of patients with HIV/AIDS. Currently in Greece, disclosing one's HIV/AIDS status is particularly difficult because the condition is still negatively associated with homo-sexuality or particularly promiscuous behavior. This can bring extra stigma and discrimination against patients infected with HIV/AIDS irrespective of its cause.

**Keywords:** HIV/AIDS Infection, Patient Rights, Health Legislation

## 1. Introduction

Patient rights (PR) are a concept under the broader category of human rights. The rights of patients as they have been depicted in international texts, such as the United Nation's Charter on Human Rights formulated post World War II in 1949. These are guaranteed in the national (Greek) legislation and can be distinguished in two categories: the rights of the patient and social rights, which include rights in the health care arena [1, 2].

Individual rights of a patient aim to protect privacy and freedom, that is to say the protection of free will and autonomy.

PRs are also protected by provisions of urban and penal legislation. On the other hand, social rights aim to guarantee that the individual has unprohibited access to all domains and activities of social life. With regard to health care, PRs are closely connected to state health care policies including the administration and organisation of health care provision [3, 4].

Historically, the first texts that mentioned patient rights directed the doctor to respect patient dignity. These were the Hippocratic writings, which constitute the foundations on which most contemporary medical bioethics rest. Furthermore,

the Hippocratic Oath, as used today in many parts of the world, still teaches the importance of confidentiality as a fundamental obligation of the doctor towards his patient by including the following pledge: *“I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death”*.

In the following centuries and during the Middle Ages in Europe it is widely acknowledged that the medical world stagnated due to an extensive destruction and loss of medical scripts and scrolls which had been preserving medical knowledge from Roman and Greek civilizations. Consequently the quality of medical practitioners was poor. However, the Renaissance, in contrast, brought about a rebirth in medical investigation and discovery including detailed studies in anatomy with an early focus on the patient per se [5].

Most notable advances occurred in the 1970s, when various social movements for patient rights led to radical changes of moral rules and, in 1973, the first official text on the rights of patients was drafted in the USA [6, 7].

This code dictated fundamental core values as follows:

- The patient has a right to discreet care with respect.
- The patient has the right to acquire from his/her healer complete and effective information concerning his diagnosis, treatment and prognosis, providing that he/she is in a state whereby this information can be comprehended. When it is medically inadvisable to provide this information to the patient it can be given to the nearest next of kin.
- The patient has the right to receive essential medical information in order to give valid consent for a treatment, except for urgent emergency cases.
- The patient has the right to deny care to the extent that it is permitted by law and should be informed of the medical consequences that this decision may carry.
- The patient has the right of privacy regarding his own program of treatment. Discussion of cases, medical counselling, examination and treatment should be confidential and carried out with respect to privacy. Those who are not directly involved in care delivery should only be present with patient consent.
- The patient has the right to have all communications and medical files concerning his/her case, kept in confidence.
- The patient has the right to anticipate that a health care provider (e.g. hospital), within in the frame of its capabilities, will extent its efforts to offer to the patient what the best available therapy is for his case.
- The patient has the right to know if the health care provider intends to include him/her in an experimental program of treatment and he may freely deny participation.
- The patient has the right to expect reasonable continuity for his/her care and to know the available resources for this.
- The patient has the right to receive and scrutinize detailed account of the cost of hospitalisation and the

final sum owed.

- The patient has the right to know hospital regulations that concern him.

Overall, a patient is entitled to receive professional health care services. When referring to nursing in particular, it is essential that the nursing code of conduct is made explicit and followed through with regard to patient rights.

The nurses' responsibility in this respect is fourfold: i.e. promoting health, preventing illness, safeguarding health status and alleviating symptoms. Thus, the importance of nursing is paramount [8]. Yet, built within the core of the nursing paradigm is the respect for life, dignity and the rights of the individual, regardless of nationality, gender, doctrine, race, age, political or social situation. Nurses constantly offer health services to the individual, family and society by collaborating with an extended network of health and care professionals.

## 2. Aim

The main purpose of this position paper is to outline nursing duties and patients' rights. The objectives are to outline nursing deontology and patients' rights by discussing critically the case of confidentiality and consent of individuals with HIV/AIDS and related issues involved.

## 3. Method

A critical debate is undertaken using resources from national and international literature. This entailed research and review papers from 1990 onwards as HIV/AIDS has become a major international health and public concern affecting individuals, families and communities alike.

## 4. Results and Discussion

The results of this critical discussion paper are organized in six distinct sections which cover holistically the topic under debate, as follows:

- Nurses and individuals,
- Nurse and practice,
- The current situation in Greece,
- Patient consent with HIV-AIDS,
- Medical confidentiality and HIV-AIDS,
- Ethical implications of HIV/AIDS patients in hospital

This typology ensures that a true nursing perspective is presented regarding the rights of patients with HIV/AIDS both nationally and internationally [9]. In this respect, it was deemed essential that results of this paper incorporate discussion as well as part of a critical comprehensive overview of a complex and challenging health care topic.

### 4.1. Nurses and Individuals

The initial responsibility of a nurse is to attend to those in greatest need. This is offered in framework of respect of the values and circumstances of the individual, maintaining confidentiality and equity. In these lines, the Greek code of

nursing deontology as published by Greek Presidential Decree (2001, clause 6) reads: “A nurse owes to demonstrate the same level of care to all patients, with assiduity and devotion regardless of religious, ideological or other patient characteristics, including economic circumstances, social situation or the gravity of illness itself” [10].

It further states that “A nurse owes respect of the patient’s personality and value and needs to take every measure necessary to promote personal freedom and the free will of the patient but also to abstain from any action to the contrary” (clause 5).

Finally, as the Presidential Decree clearly dictates, in every case a nurse must warn the patient of the benefits and potential risks of his/her treatment within the limitations of their professional role and to ensure that patient consent is obtained. In this sense, a nurse can be viewed as one of the patient’s closest advocates.

#### 4.2. Nurse and Practice

The nurse bears personal responsibility for his/her nursing practice and for the care delivery within the framework of continuing education and lifelong learning. In that sense, the highest levels of care that can be achieved for each particular case should be met. When the nurse delivers care within the appropriate scientific and professional standards, this creates additional patient confidence [11].

The code of professional conduct also foresees this by stating clearly that: “The nurse owes to protect the patient from any damage or danger within a health care provision setting, creating a secure and safe environment” (clause 8).

Routine clinical nursing practice also: “owes unlimited respect to the private sphere of the patient by refraining from any action or omission that might harm the confidential character of patient information which practiced at the exercise of nursing duties (clause 9).

Finally, in a protective mode for both the patient and the nurse, the nursing code stipulates that: “A nurse owes to deny his/her services in cases where he/she judges that he/she does not have the required knowledge or experience” (clause 12).

##### *The current situation in Greece*

Following international tendencies and other social developments, Greece introduced patients’ rights with direct legislation in 1992. Prior to this, their protection existed indirectly via Constitutional, Urban, Penal and Administrative Rights Legislation as well as on disciplinary regulations and the provisions reported mainly in the framework of medical obligations towards patients [12].

Therefore, when a patient enters the hospital, he/she maintains his/her legal entity, remaining above all a person as a whole (όλον), as well as a citizen with constitutional rights. Yet, after the 1992 legislation on patient rights, efforts to promote this notion have not been sufficient. Debriefing patients on their rights, especially with a view to what they were entitled to claim, was not widely applied. Then, in August 1997, the protection of patient rights was reinforced within the restructuring of the National Health Care System [13].

##### *Patient consent with HIV/AIDS*

A complex set of dilemmas, responsibilities and other issues may arise when treating patients with Human Immunodeficiency Virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS) in hospital. As a rule of thumb, and apart from exceptionally urgent or extremely serious cases, the doctor cannot proceed with a medical intervention without the direct or indirect acceptance (consent) of the patient. In this context, checking for HIV/AIDS is only allowed when the patient explicitly consents so. Therefore, as a general rule, if the patient has not been fully informed about a blood test for HIV/AIDS, taken without his/her consent, then this individual has been personally offended and his/her right for respect of his/her private life has been violated [14].

Yet, health care services should also provide the opportunity for anonymous testing for those who have special personal or other circumstances which may hinder their access to such testing. In any case, the physician has an explicit obligation to fully inform the patient of the results of the examination. However, if the doctor perceives that the patient is not suitably prepared for such information and there is a possibility of psychological breakdown, other specialists should be available to provide extra support. The seriousness and peculiarity of AIDS is likely to impose a closer application of the above mentioned principle, the infringement of which may involve sanctions for the doctor. Not informing the patient who tests positive for HIV/AIDS, is medical negligence, carrying serious legal implications [15].

Thus, the basic premise for testing a hospitalized patient for HIV/AIDS (after his/her consent) should be purely based on a clear diagnostic, therapeutic or other clinical reasoning, as in cases of differential diagnosis such as infectious diseases or swollen lymph glands. An exception to consent would be in cases of loss of conscience, intellectual impairment or underage patients which need to be met individually, according to the rules of medical deontology [16].

The regulation for minors or patients under guardianship, states that testing should be conducted with the consent of the individual who acts on the patient’s behalf. Still, if the minor is considered to be adequately mature, his/her opinion can also be sought. In any other case, the test for HIV/AIDS should resemble the consent for other serious conditions, thus, being detailed and not general and vague [17]. The consent in this case should also be serious and spontaneous, i.e. it should correspond to the patient’s genuine will, and be given freely without threat of violence, fallacy or indirect intimidation.

The test can be done without patient permission only in very few cases, such as when there is a direct risk for his life due to the delay of seeking for consent or when the patient is comatose and it is impossible to find a next of kin. There are voices supporting that as testing without consent is routine practice for other contagious diseases such as syphilis or tuberculosis which may also lead to social stigmatization, this could also apply to HIV/AIDS. Yet, there is a fundamental difference as these illnesses can be cured, consequently there is a direct clinical benefit for all parties involved as individuals can return to their previous state of affairs [18].

To date, there is no overall curative treatment for HIV/AIDS sufferers, thus, the patient is considered contagious for life. However, the British Medical Association excludes the possibility of testing without the patient's consent and warns doctors that such actions might possibly create conditions for their prosecution [19]. As this is a delicate and complex matter, and in order to define the borders of patient-doctor rights and obligations, in the most reasonable and fair way, and vice-versa, it is essential that special cases are scrutinised in collaboration with legal advisors. Thus, certain exceptional and controversial cases may overtake norms with the interpretation of various overlapping national and international legislation [20].

### **4.3. Medical Confidentiality and HIV/AIDS**

As widely acknowledged, medical confidentiality constitutes one of the main duties of health care providers and at the same time one of the fundamental rights of patients. Thus, principles concerning this matter deserve special attention especially in the case of HIV/AIDS which is accompanied by a complexity of moral and ethical questions. The practice of medical confidentiality is obligatory in all health care situations, not only purely medical situations. Confidentiality should be safeguarded in every case. In this light, for example, the reporting of incident rates of AIDS for official statistical purposes should also be conducted under strictly controlled conditions in order to prevent the violation of confidentiality [21].

If it is judged essential, the possibility of establishing new special conditions can be introduced via relevant legislation. A local practice regulation that is in effect in a clinical setting of a Northern Greek hospital is the establishment of an anonymity coding system for patients with HIV/AIDS. Thus, the patient's name is substituted by the first two letters of his/her surname and the first three letters of his/her name. This code appears on all requests and tests of the patient in the hospital while full details are kept separately on the ward [22].

In the case of the patient's or even the doctor's death, the obligation for confidentiality remains. Yet, this can be overturned, by a special provision of law when it is judged that there is a certain public health risk involved. The patients' medical files are also anonymous and confidential so that research can be conducted if necessary [23]. The employer of a patient with HIV/AIDS is also compelled to confidentiality. By the same token, confidentiality is to be kept in effect in a school environment, by teachers or school-nurses. Overall, health care providers are in no case obliged to notify the patient's workplace or school environment of his/her condition despite a widespread social viewpoint that such notifications would 'protect' the public at large. Rather, the public should be aware that it is individual's responsibility to act accordingly. In return, this is claimed to be more beneficial for the public itself. Any other tactic leads to isolation and patients will suffer discrimination which is unacceptable from an ethical point of view [24].

Moreover, the doctor does not have an obligation to inform the sexual partner of the patient. Such an obligation arises

only in the case of spouses and only when the doctor suspects that the patient is not going to collaborate in informing his/her spouse accordingly. In any case, however, the doctor has to inform fully the patient of this intention. Thus, if the patient has not been convinced adequately to announce the diagnosis to the spouse, then the doctor (and after exhausting all methods of persuasion), may follow a due legal process and, after it is judged essential, may be provided with authorisation to announce the diagnosis to the spouse. Yet, contemporary Greek reality is different as in most cases complex family, societal and other issues involved hinder the free-flow of established processes.

However, the international standpoint is clearer. According to Njozing et al., (2011) partner notification for HIV/AIDS is an essential part of counselling as it may help to prevent secondary transmission, promote early diagnosis or prompt treatment of HIV/AIDS patients' sexual partners and thus should be exercised accordingly [25]. Still, many counsellors find many HIV-positive patients reluctant to notify voluntarily their sexual partners [26].

Kantian theory postulates that humans deserve to be treated with respect as ends in themselves and not as means to another individual's ends. Yet, it could be argued that HIV/AIDS patients should not be forced to disclose their health status for the benefit of specific others or the greater benefit [27]. There are many instances when violations of privacy have been observed, mainly due to recent technological advances, such as social media, which make it easier to break confidentiality and communicate such sensitive information. Thus, it takes considerable effort in the part of all, to respect confidentiality as a fundamental patient right and act accordingly at all times [28].

### **4.4. Ethical Implications of HIV/AIDS Patients in Hospital**

Patients with HIV/AIDS should be treated in hospital just like any other patient group. The risk of cross-infection to health care personnel is minimal and arises from careless handling of needles. Under no circumstances is refusal of hospitalisation of such patients justifiable. Besides, the doctor does not have the right to refuse the benefit of his services as this would not only be characterized as anti-deontological but it could also involve penal or civil liability for himself. Furthermore, this could also extend to nursing personnel and the health care unit as a whole. It goes without saying that health care institutions provide all nursing personnel with appropriate measures of protection, such as gloves, disposable overalls and disinfectant agents. Only in the case of staff pregnancy, or reasons of special circumstances, may a health care professional be excluded from treating such patients [29, 30].

As the hospital has an obligation to accept and treat HIV patients it also has a responsibility to recruit suitably trained and educated personnel [31]. If however, these circumstances are unavailable, the patient should be informed and be given the choice to be transferred to another hospital, suitably staffed. Yet, this policy has been known to be a point of friction between various hospitals and the Units for Special

Infections (USIs).

Nevertheless, clinical experience has shown that HIV/AIDS patients end up in USIs even when requiring hospitalisation for situations not related to their prime diagnosis, such as a strained shoulder or eye disorder. Thus, other hospitals in the same city or departments within the same hospital have been known to stall or refuse admission of such patients claiming that: «*we are being [unfairly] unloaded with a risky incident*».

Although the coding system in use for HIV/AIDS patients within a hospital environment ensures patient anonymity, it may unfortunately stigmatize at the same time. Such is the case of the Magnetic Resonance Tomography (MRI) department where a contrast agent is to be used. MRI personnel may demand that USI nurses install an intravenous line in situ prior to transfer to their department.

Still, ethics and deontological issues regarding HIV/AIDS remain complicated, challenging and unsolved in many cases. For instance, when a surgeon denies operating on a patient with HIV/AIDS, in order to protect their own health, they are liable for malpractice. Yet, what if the surgeon himself/herself is HIV/AIDS positive? Should the hospital deny access to the operating room or should an additional patient consent be obtained accordingly, i.e. to allow for a surgeon with HIV/AIDS to operate [32, 33].

## 5. Conclusions

Nursing encompasses various ethical paradigms and concepts, thus broadening the horizons of those caring for patients with HIV/AIDS. The complexities of ethical dilemmas concerning this condition have remained highly controversial over the past three decades and, hence, a solid foundation for future postulation and debate is needed.

The respect for patients' confidentiality is a fundamental principle in medical ethics, and also a legal duty that health care providers owe to all patients. However, the respect of absolute confidentiality has been a subject of debate and controversy, particularly in the case of patients with HIV/AIDS.

With the advent of the HIV/AIDS epidemic, this debate has been re-echoed if confidentiality should be compromised when HIV-positive patients refuse to notify voluntarily those at risk of infection and especially their sexual partners.

Currently in Greece, disclosing one's HIV/AIDS status is particularly difficult because the condition remains negatively associated with homo-sexuality or particularly promiscuous behavior both of which are social condemned per se in contemporary Greece. This can bring extra stigma and discrimination against patients infected with HIV/AIDS.

Therefore, the ethical, legal and moral dilemmas regarding patients with HIV/AIDS remain controversial and challenging. Although confidentiality is an important issue in the staff-patient relationship, there are certain exceptions where this can be subverted. However, this should balance the interests of the patients, their sexual partners, health care staff and society as a whole. This process can only be facilitated by

globally adopting a human rights framework which recognizes both individual and collective rights.

This will ensure that HIV transmission is significantly curtailed, and those at risk identified in time and provided with the necessary health care services.

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