Patient's Rights and End-of-Life Decisions: The Albanian Experience

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Abstract

As human beings we are bound up with the medical profession. It is certain that at some point in our life we rely on their help. Even if such help is avoided throughout life, some life activities involve recourse to medical care.

During the exercise of its activity the medical profession is faced with many ethical dilemmas, where the solution is not in the law, where choice and decision making become difficult in terms of ethics and where they must rely on their values and judgments. That's why the involvement of the medical profession in everyone's lives makes the understanding of the law governing the medical profession extremely important.

Patient rights are part of human rights.

This article's aim is to present one important patient right - the right to die. Whilst is accepted the increasing role of the medical profession in determining the shape of the law in medical care, this article focuses on understanding how different courts deal with cases involving the right to die. The article offers a framework on patient's right to die in Albania, and the well-known international experience on the issue.

Introduction

The concept of “A right to die”

At the heart of liberty is the right to define one's own concept of existence, of meaning of the universe, and of the mystery of human life (1). As Abraham Lincoln, speaking in Baltimore in 1864 said, the understanding of rights, life and liberty is different for different people (2).

The right to die raises many difficult questions in medical care: What is the right to life? When life, and therefore the right to protection of life by law, begin or end? May, or must, the state protect the right to life even of a person who does not want to live any longer, against that person's own wishes? Is it acceptable to provide palliative care to a terminally ill or dying person, even if the treatment may, as a side-effect, contribute to the shortening of the patient's life? Should the patient be consulted on this? Do people have, not just a right to life and to live but also a right to die as and when they choose? Do they have the right to decide on what they consider to be a “good death” (3)? Can they seek assistance from others to end their lives? Can the state allow the ending of life in order to end suffering, even if the person concerned cannot express his or her wishes in this respect?

The answer to such questions might be easier in cases arising by requests of mentally fit patients, who request to die for they are unable to commit suicide themselves. The situation is very different in cases of patients who cannot express their opinions, such as patients in a persistent vegetative state (PVS). In such cases the question that arises is whether they too have a right to die (4).

The Oxford English Dictionary defines the ‘right to die’ as ‘pertaining to, expressing, or advocating the right to refuse extraordinary measures intended to prolong someone’s life when they are terminally ill or comatose’ (5). Such right includes issues of suicide, active euthanasia (the deliberate action to hasten death), passive euthanasia (allowing a person to die by refusal or withdrawal of medical intervention), assisted suicide (providing a person the means of committing suicide), and palliative care (providing comfort care which accelerates the death process).

It is impossible to talk about a right to die without considering the acts or omissions of the physician. It's obvious that if a family member, friend or relative helps someone die, in the comfort of their own house, they will definitely face prosecution. The situation changes in medical care. Obviously it would be easy for the state to ban any sort of assistance from doctors to help their patients to release suffering and pain, and sanction punishment by law to any doctor that would commit such actions. But then, when talking about patients that can not commit suicide themselves, would such actions be considered as state interference on their right to put an end to their life? Is there such a right?

A person may decide to end his or her life not only actively, i.e. committing suicide, but also passively such as refusing life saving treatment, food and water. However, even in such situations the possibility remains that another person will get involved, not to assist in suicide, but to make dying comfortable and
painless. Terminally ill people or those unable to commit suicide themselves rely on their doctors to give an end to their lives.

Doctors have a duty of care which consists on diagnosing, treating and advising. These obligations are both moral and legal. Treatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning (6). A doctor’s duty of care is to take reasonable steps (as other reasonable doctors would) to save or prolong life or to act in the patient’s best interests (7). Although in most instances doctors would prescribe the drug for the purpose of pain relief, it is arguable that at times, they may in fact do so to assist their patients to put an end to their suffering.

When deciding on end-of-life cases judges are faced with some really important questions: Is there a “right to die,” “a right to determine the time and manner of one’s death”, a “liberty to choose how to die,” a right to “control of one’s final days,” a right to choose a humane, dignified death,” and “the liberty to shape death”? Do terminally ill persons have a right to avoid both “severe physical pain” and “the despair and distress that comes from physical deterioration and the inability to control basic bodily and mental functions” (8)? Is a liberty interest implicated when the state blocks a person from seeking relief from severe pain or suffering?

There are two distinctive views of the right to die: the right to die as a negative right, which requires a duty of non-interference and calls for non action from others; and the right to die as a positive right, which entails not only a duty of non-interference, but also “the duty to help, at least in the cases where the right-holder would not be able to do the thing without help” (9, 10).

In order to benefit from the existing negative right to die, one must be competent to make a decision. Further to this, the person should be physically able to carry out the act of suicide. Therefore, a person contemplating suicide should begin and end the whole process by oneself. Any sort of assistance provided either “before the fact”, ‘during the process of attempt to commit suicide’ or ‘after the attempt’, would potentially render the assistant an offender and subject to prosecution.

Some judges are in favor of protecting the right to die, assisted suicide and voluntary euthanasia, while other focus on state’s interest in the protection of life. For those who support this right, it is tempting to argue that the court should recognize the right as fundamental and, under traditional fundamental rights jurisprudence, effectively stop all infringements. The problem with such an approach is that to do so would undervalue the state’s legitimate interest in preserving life in all forms when a state chooses to adopt a pro-life policy. The policy that must be adopted must balance these two interests so that they may coexist to the fullest extent possible (11).

There is though, arguably, a “right to die with dignity,” which includes as one of its core aspects a right to avoid “unnecessary and severe physical suffering” (12). A successful claim to assisted suicide would require a showing of a need to avoid “severe physical pain,” and any physical pain can be avoided with either pain control medications or “sedation which can end in a coma”. Faced with the argument that assisted suicide is the only way to respond to the severe suffering of some dying patients, the courts have observed that these patients can turn to the alternative of terminal sedation (12). However, terminal sedation is essentially a form of euthanasia.

Many are of the opinion that withdrawal of life sustaining treatment on patients in a persistent vegetative state is also another form of euthanasia. One possible justification for distinguishing between euthanasia and withdrawal of life sustaining treatment is the distinction between acts and omissions, or between killing and letting die. Treatment withdrawal, which indisputably involves doctors doing something, is a good example of conduct which lies on the boundary between acts and omissions, because it could easily be described as an action. It is by taking into account the surrounding circumstances, and not by labeling what the doctor does as an omission, that we can ascertain whether his conduct is acceptable. The morally relevant fact is not whether what the doctor does is an omission or an action, but rather whether the background against which the decision has been taken justifies the doctor’s conclusion that life, in these circumstances, should not be artificially prolonged (14). Certainly there are cases where refusal of treatment is motivated by the desire to avoid a continued life of suffering and other cases where it is only the treatment itself the individual seeks to avoid.

While deciding on right-to-die cases, the courts have emphasized the distinction between withdrawal of life sustaining treatment and suicide assistance. Withdrawal of life-sustaining treatment is permitted because the patient dies from the underlying disease, not from the active intervention of the physician (15).

Opening the door to assisted suicide for terminally ill persons could pose too great a risk of suicide for persons who are not competent, who are not terminally ill, whose desire for suicide would abate with
treatment for mental depression or with validation from others of the value of their life, or who are vulnerable to influence by family members and physicians concerned with the financial and psychological burdens of caring for the patient, nevertheless it is working for the Netherlands (16).

The majority of individuals and countries are of the opinion that ... “Legalization of physician-assisted suicide or euthanasia would “undermine the trust that is essential to the doctor-patient relationship” because physicians would be causatives of death as well as healers of illness. A right to assisted suicide for the terminally ill inevitably leads society down the slippery slope to assisted suicide for patients, who are not terminally ill. Once “we shall permit assisted suicide for some persons, there will be no reason for denying it to other persons who claim great suffering (17).

Even though the majorities of states worldwide do not accept and ban any form of assisted suicide, when it comes to decision-making the judges, themselves, are of different opinions. As a result it is very difficult to have a sharp opinion whether accept some sort of assisted suicide or be against any such form.

Discussion

Albanian case law on the right to die

In Albania, the Constitution protects the right to life and health care (18). According to the Constitution the protection of life is an important constitutional requirement. The concepts of life and dignity are important constitutional values considered as the source of all other fundamental rights and freedoms. The individual and his life are of superior value for the state.

Regarding individual’s right to die, in Albania both forms of euthanasia and assisted suicide are banned and considered a criminal offence. The problem consists in the fact that this is not literally provided by law, but it is through the interpretation of law that such actions are considered criminal offences.

In Albania, patients’ rights are guaranteed and protected by the Constitution, The European Convention on Human Rights (as a ratified international agreement), Law ‘On health care in the Republic of Albania’ (19); Law ‘On public health’ (20); Law ‘On the regulated professions in the Republic of Albania’ (the part that provides duties and obligations for the health care professionals) (21) and The Ethical Code on Medical Deontology (22).

Albania’s Criminal Code provides criminal acts against health due to negligence (23). None of these articles provides limitations on the right to die or euthanasia. It is only through the interpretation of law ‘On health care in the Republic of Albania’ and the Albanian Code of Ethics and Medical Deontology that euthanasia is considered as a criminal offence.

The law ‘On health care in the Republic of Albania’ provides that, for the safeguard of the ethical rules and medical deontology by the health care professionals, Professional Orders are created. Professional Orders’ duties and activities are provided by their respective laws (24). Such laws provide the duty of the physicians to apply the Code of Ethics and Medical Deontology.

According to this Code relief of suffering and pain is one of the fundamental duties of the physician towards its patient. This is particularly important while treating a dying patient. The physician, except treating the patient, must also offer spiritual assistance and care, in respect of patient’s wishes and religious beliefs, safeguarding his dignity until the end of his life. The physician must inform the family of the patient on his condition and try to get their cooperation in relieving the suffering of the sick (22).

Acceleration of the end of life or death provocation is contrary to medical ethics. If the patient is unconscious, with no hope to live, the doctor must act according to his judgment in patient’s best interest. The physician must decide on the therapeutic actions he will undertake, after consulting his colleagues and patient’s closest family members (22).

As noted, the Albanian Code of Medical Ethics and Deontology allows a margin of appreciation regarding euthanasia, stressing the importance of patient’s dignity and best interest, while prohibiting any form of acceleration of end of life or provocation of death.

In the Albanian jurisprudence there is no case of active or passive euthanasia, or of assisted suicide. Not only there are no such cases, but there is an immediate need for the Parliament to regulate the activity of physicians on such cases. The state must also take necessary steps to inform not only patients on their rights on medical care, but also the physicians on their rights and duties.

Even to the questionnaire prepared by the European Health Committee, followed and assembled by the Parliamentary Assembly of the Council of Europe, which led to Recommendation 1418 (1999) ‘Protection of the human rights and dignity of the terminally ill and the dying’ (25), Albania answered that there was no law on euthanasia, that the term was not included in the Albanian Criminal Code, therefore there were no
sanctions against it, that the only provisions on the Albanian Criminal Code could be found on the chapter ‘On offences against life and health’ and that the activity of the physician was provided only in the Albanian Code of Ethics and Medical Deontology.

At present, the activities of Albanian physicians in end-of-life situations are still not regulated either by law, by decision of the executive power, or any other regulation. Other Albanian researchers have also suggested the immediate need for such legislative regulations (26).

The legislative reform should be coupled with a program to promote the understanding and use of procedures on end of life or terminally ill patients amongst the general public and the legal and medical professions. The patients must have greater access to information about their rights regarding medical treatment. The physicians must understand and apply not only the law but they should understand also the consequences they’re faced with if they do not obey the laws in force regarding medical care. Patient’s dignity and best interest should be protected, as should patient’s health and life.

Conclusion

The involvement of the medical profession in everyone’s lives makes the understanding of the law governing the medical profession extremely important. It is certain that at some point in our lives we are forced to rely upon the medical profession. The almost certain involvement of the medical profession in achieving good health makes the laws governing the medical profession and the rights of the patients vitally important.

Obviously the right to life is fundamental in our scheme of values. Such right, considered as the cornerstone of all individual rights and freedoms describes the belief that a human being has an essential right to live, particularly that a human being has the right not to be killed by another human being. Nevertheless, the interest in the preservation of human life is not itself sufficient to outweigh the interest in liberty that may justify the only possible means of preserving a dying patient’s dignity and alleviating her intolerable suffering (26).

The right of the patient to die today should be considered in the light of the changes society is going through and of new approach towards human rights.

References

4. Death is defined in Chambers Twentieth Century Dictionary as ‘the state of being dead; extinction or cessation of life’, http://archive.org/stream/chambersstwentie00daviiala/chambersstwentie00daviiala_djvu.txt, [accessed 18.03.2013]
14. Memorandum by Professor Emily Jackson, Chair of Medical Law, Queen Mary, University of London. http://www.publications.parliament.uk/pa/ld200405/ld

16. Articles 293 and 294 of the Dutch Penal Code make both euthanasia and assisted suicide illegal, even today. However, as the result of various court cases, doctors who directly kill patients or help patients kill themselves will not be prosecuted as long as they follow certain guidelines. Washington v. Glucksberg, 117 S. Ct. 2258 (1997) (No. 96-110), p 2273-74 (Breyer, J., concurring).

17. Articles 293 and 294 of the Dutch Penal Code make both euthanasia and assisted suicide illegal, even today. However, as the result of various court cases, doctors who directly kill patients or help patients kill themselves will not be prosecuted as long as they follow certain guidelines.


20. Law no 10138, dated 11.05.2009 ‘On public health’.


22. Albanian Code of Ethics and Medical Deontology, adopted by Decision nr.9, dated 11.11.2011 of the National Council of the Albanian Order of Medics: Art 38 ‘Relief of suffering of the dying patient’, Art.39 ‘Non acceleration of death’. Albanian Criminal Code, section IV. Article 91 of this Code provides: ‘Serious injury due to negligence constitutes criminal contravention and is punishable by fine or imprisonment up to one year’. Article 96 provides: ‘Incorrect medication of patients from the doctor or other medical staff, […] is punishable by a fine or up to five years of imprisonment.’


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