The Right not to Live

(A New Dimension of the Right to Live in End of Life Decisions)

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Abstract—In the old days the doctor was expected to maintain the patient’s life, even disregarding his wishes. The principle of beneficence and the right to life justified this understanding of the doctor’s duties and minimized the value of self-determination.

However, the juridical framework of end of life decisions was changed by new conceptions regarding the role of medicine, the patient-doctor relationship and the connection between human life and self-determination, therefore, giving raise to the so called right not to live, as an conjunction of the right to life with the right to self-determination.

Keywords-component: European Court of Human Rights, euthanasia, human dignity, right to life

I. INTRODUCTION

The right not to live is a new juridical figure, and a very controversial one, created by the growing awareness that not all lives are a valuable good, since some of them impose such huge burdens on the life holder that it is not a dignified life and it may even reach a kind of torture. In those scenarios it is not the right to live that is at stake anymore, as it turned into an imposition of living.

The controversy surrounding the right not to live is enormous, since many believe that life is always a blessing, no matter the living conditions. In addition, it is claimed that this right is a contradiction in itself. In this article we intend to dismantle both assumptions.

The scenarios where this new fundamental right is more frequently claimed are the ones promoted by new developments in technology and science, able to prolong human existence beyond the average life expectancy, but sometimes at expenses of huge suffering, loss of independence and, therefore, loss of dignity.

II. THE RELATION BETWEEN DOCTOR AND PATIENT

Until recently the traditional rule concerning the doctor-patient relationship allowed the doctor to act without any need to previously require the patient’s consent. The doctor’s exclusive concern was not to harm the body, health or life of the patient (and even this is a recent obligation, given that doctors have traditionally enjoyed a privileged status), completely disregarding the patient’s will and self-determination in matters related with medical care.

Differently, nowadays the patient’s consent is stated as an autonomous lex artis [1], i.e., good medical practices require the prior consent of the patient. The violation of this rule of conduct involves disciplinary and juridical responsibility, even if the patient has not suffered any physical damage and, on the contrary, his physical state has improved because of the doctor’s intervention.

The reconfiguration of the doctor/patient relationship [2] results from the understanding that the basic fundamental rights of the patient need to be respected, namely the liberty to decide matters pertaining to his body, health and even life [3,4].

III. THE PATIENT’S INFORMED CONSENT IN MEDICAL LAW

A. The crime of arbitrary medical interventions

One of the core principles of medical law is, presently, the recognition of the patient’s consent as the cornerstone of the doctor-patient relationship. Therefore, the doctor can only act based on the prior consent of the patient, which must be a free and informed consent, in line with the provisions of most of the medical Codes of Ethics.

In addition, same Criminal Codes, as the ones of both Portugal and Macao, consider that medical proceedings without the referred consent configure a crime of arbitrary medical interventions [1-5]. Although the guiding principle of our criminal law is the in dubio pro vita principle, the fact is that in those provisions the lawmaker gave prevalence to the right to self-determination over the right to life.

This implies that, whenever the patient refuses a particular medical intervention, the doctor cannot act against his will, irrespectively of whether he is a dying patient attacked by a lethal disease or, conversely, a patient with a completely curable disease which could be treated, in other words, even if his decision is objectively unreasonable.

The consent does not have to be necessarily provided in written form, since only in exceptional cases the law requires that formality, such as abortion, sex changes, amputation,
reproductive technologies and risky proceedings. The reason is that consent is not a paper, but a relationship of trust, which never can be substituted by a piece of paper (nevertheless, in a litigation context the existence of a written document substantially facilitates the proof of the existence of the mentioned consent).

B. Presumed consent

In the absence of a previous manifestation of consent the case will be settled based on the figure of presumed consent, evaluated by the physician in accordance with the supposed will of that particular patient [1-6].

That will be the case in two particular situations. Firstly, regarding patients momentarily unable to express their will but, due to the emergency situation, it is not feasible to wait for the patient to recover and provide the required consent (an eventuality that may never occur). Secondly, when the patient has only consented a specific medical act, but during the authorized procedure the doctor concluded that the intervention should be extended or modified; however, the patient is by then sedated and it may be wiser and secure to proceed without a reformulation of consent, because the postponing of the intervention would cause the patient more harm than good. In both scenarios the doctor may intervene without a prior manifestation of consent, as long as there are no strong reasons to believe that this consent would be denied if the patient where in conditions of expressing a decision.

Presumed consent is based on the supposed will of the patient (subjective criterion) and not having in consideration what is the greatest good for the patient in the perspective of society in general (objective criterion).

Nevertheless, this subjective consideration is not always accessible to the doctor, especially when the patient is a complete stranger and there are no relatives or friends to provide useful information about his personality and beliefs. In that particular situation the doctor is required to make a decision according with good medical practices and the principle of beneficence. Therefore, in the absence of a serious indication that the patient would refuse the treatment, the physician must act, since one of the fundamental principles of all legal systems, including the ones of Portugal and Macao, is still the protection of life.

To only limitation to this rule refers to the cases when, even in absence of a refusal of treatment, the medical act must be refrained, because it would be against lege artis to provide medical treatment to that patient, since his health condition is irreversible and moves towards a close death.

Note, however, that this conclusion does not preclude medical assistance to those patients, as palliative care or any other measures intended for reducing pain and suffering. It only prohibits proceedings that are not effectively therapeutic and merely prolong the period of human existence without additional benefits for the patient.

IV. THE VARIOUS FORMS OF EUTHANASIA

The term euthanasia expresses the assistance to death, that is, the support provided to a severe and hopelessly ill person, according to his will (real or presumed), in order to enable a death in conditions that the patient believes (or there are reasons to assume that this is his conviction) humanly worthy [3,4,7,8].

One might be tempted to conclude that, since the law provides a broad respect for the will of the person when it comes to decisions about the body, health and life (as it is demonstrated from the non-punishment of suicide and the criminalization of arbitrary interventions), then, acts of third parties (the doctor, a family member) in accordance with that will won’t be punished.

However, and despite the fact that to the person himself everything is permitted, to third parties virtually everything is refused, at risk of practicing a criminal conduct, such as an homicide, a murder on request or an assisted suicide.

The legal assessment of this practice is not uniform and it varies depending on the concrete form of euthanasia [1-5].

A. Active direct euthanasia

Active direct euthanasia translates into acts (usually administration of medication or other lethal substances) aimed to directly cause the death of the patient, but – and this is a particularity to be noted – to protect him from the higher suffering caused by his disease.

Despite the motivation of the agent, medical deontological codes tend to repel this practice. In parallel, most legal systems still denote some reluctance in accepting its legitimacy and frequently consider it as a form of homicide, though usually a less severe one, therefore, less punished.

However, an increasingly number of scholars has been arguing that this conduct should not be punished when practiced by a doctor. In order to justify this solution several distinct juridical figures are invoked, such as the conflict of duties or the state of necessity. Both of these figures exclude the criminal responsibility of the doctor.

B. Active indirect euthanasia

Active indirect euthanasia relates to those situations where the doctor does not want to end the patient's life, but solely alleviate his suffering, however, his conduct has the parallel effect of accelerating the patient’s death.

What distinguishes active direct euthanasia from active indirect euthanasia is the intention which moves the doctor, since in the last case this intention coincides with the relief of the patient's suffering, not with the act of killing. Therefore, the resulting death is a foreseeable consequence, however, not a desired one, whereas in direct euthanasia death is the main objective, although aimed to a different purpose than simply killing someone.

The ethical and legal framework of active indirect euthanasia is still very controversial. A more moderate and
classical position advocates that it is an unlawful manslaughter, in which the unlawful nature is subsequently removed, either due to the patient’s consent, either to a criminal law figure called justifying state of necessity. This solution is based on the idea that the protection legally due to the juridical value of “human life” can only be removed in a subsequent evaluation, which excludes the wrongfulness of the conduct. But prima facie this conduct is considered illegal, since the exclusion of wrongfulness only operates in a subsequent moment.

A more radical thesis - and currently dominant – sustains that this conduct does not have a criminal nature. The reason is that every modality of homicide includes, as its typical element, the intent to kill another person, which is inexistet here, as we continue in the presence of a therapeutic intent. Furthermore, the best medical practices currently existent underline the legitimacy of medical conduct aimed to avoid human suffering. Indeed, in the present state of medicine leges artis are firmly against the medical prolongation of physical existence at the expense of the suffering and humiliation of the patient.

However, in order to escape from the qualification of a criminal conduct, some requirements need to be fulfilled by active indirect euthanasia. First of all, the primary reason that guides the doctor’s conduct must coincide with the intention of alleviating the patient’s suffering. Secondly, it is required that the patient be subjected to intense suffering. Indeed, a very controversial requirement relates to the health status of the patient, in particular, whether it must be demanded that death is an inevitable result in the very short term or if this requisite is not essential, therefore allowing active indirect euthanasia in patients that, thought subject to intense pain, are not in the verge of fading. In our opinion this second solution is more reasonable and fair and actually is the one most widely accepted by the dominant doctrine on this matter. In fact, the reasoning that justifies the lawfulness of active indirect euthanasia also applies to patients who may survive a few more years, as long as subject to a high degree of suffering. Finally, it is required the express or implied consent of the patient.

Active indirect euthanasia may also operate in unconscious patients. However, in this scenario the evaluation and justification of the medical conduct will not be based in the patient’s consent (except if it is a presumed consent), but on the refusal of medical obstinacy. Indeed, medical interventions may be censured based on the combat to medical futility, which is considered, ethically and juridically, a wrong medical practice.

C. Passive euthanasia

What characterizes passive euthanasia is the fact that the death of the patient is caused by the omission of the physician regarding medical procedures (not initiate the necessary medical act or subsequently suspend proceedings already started), therefore allowing the evolution of the process of death triggered by the patient’s initial health condition.

Traditionally it was sustained that the doctor had a systematic duty of maintaining the patient’s life. Nevertheless, this duty only exists to the extent of the patient’s desire to be kept alive. Otherwise, in the absence of such a desire, the doctor should not intervene. Rather, the medical intervention in this context - that is, against the patient’s will - would certainly be considered a criminal act, at least in legal orders that underline the patient’s self-determination, as for instance the Portuguese and the Macanese, where the doctor is forbid to intervene without the patient’s agreement, even if it is a life-saving treatment.

Actually, the duty of maintaining the patient’s life ceases, regardless of the patient's refusal, as long as the medical intervention can be deemed ineffective. As stated before, to keep alive a patient that is in a comatose state, without scientifically founded expectations of recuperation, is not in accordance with the best medical practices, neither respects human dignity.

D. Dysthanasia and ortothanasia

Ortothanasia can be characterized as the repulse of the artificial prolongation of life when the patient has already started the process of death (in this sense, is the exact opposite of medical futility). It does not create an independent cause of death, since such a cause is already underway. On the contrary, it merely states the omission of means whose only effect would be to timely drag the process of death, without any additional benefit to the patient.

In other words, ortothanasia expresses the recognition that science is still limited and the associated rejection of therapeutic futility. Consequently, it is generally accepted as a good medical practice and courts do not punish the doctor who applies ortothanasia. The principle of beneficence includes the relief of pain, the restoring of health and organ function and the prevention or delaying of the disease’s progression. But because the principle of beneficence aims the improvement of the patient’s quality of life, sometimes it may demand the omission of proceedings whose consequences would be the inconsequent prolongation of human existence. Human dignity is not maintaining life (its extension) at any cost and at any price [3-10].

The prolongation of life can be done if the patient expressly so desires. Nonetheless, even in this context the physician should evaluate the specific situation and evaluate whether the patient's request risks to configure a violation of leges artis based on medical futility, the so-called dysthanasia.

In addition, the doctor should also determine whether the therapeutic measures applied to that particular patient would be totally ineffective in his specific situation, whereas they would be useful, and even indispensable, to other patient whose clinical condition permits recovery [7,10]. This is a crucial evaluation in times of economic crises and scarcity of medical resources.
E. Futility and therapeutic obstinacy

Medical futility may be characterized as the artificial prolongation of the dying process, often causing suffering to the patient, even knowing that in the present state of science medicine is unable to cure the patient or even to improve his health [9].

There is no medical or legal accurate definition of medical futility, much less an enumeration of acts that are futile. But nowadays it became clear that the physician must refrain from acts that will not maintain or prolong the patient's life over an attendable period of time and in dignified conditions of existence, but, conversely, will simply increase pain and discomfort. Therefore, in a scenario of a certain and painful death, in which the patient reveals intense suffering, the physician shall try to alleviate this suffering instead of prolonging life at all cost. It is the right to a dignified death - ultimately, human dignity - to enforce this rule.

However, the enunciation of this general principle does not make it easier to identify which specific acts are therapeutic futilities. This qualification varies depending on latitudes and longitudes, because, for instance, in the United States acts such as "turning off the machine" raise far less controversy. It also depends on the intimate personal convictions of the person who decides. In effect, the decider will be more prone to prolong treatments to exhaustion if he shares the understanding of human life adopted by Catholic doctrine, according to which human life is an asset that belongs to God and not to the person. Another important conditioner element is the position in which the agent acts, since when deciding as a physician the evaluation will probably be different compared to when deciding as a patient’s relative. The moment in which the question arises can also induce the final solution, in the sense that what today is considered medically unjustified, since recovery seems impossible, may become fully acceptable when the medical act in question turns to be a routinely and successful treatment. Finally, another important criterion to be held in consideration is the condition of the patient, inasmuch as a treatment can be disproportionate in a patient with advanced age and attacked by various health problems, but entirely proportionate in a young healthy patient [4].

Given all these constraints we can only state that some acts may, under certain circumstances, be classified as therapeutic futility. This is the case of cardiopulmonary resuscitation in patients with a lethal medical condition; measures of advanced life support for patients in a persistent vegetative state; use of aggressive and invasive interventions such as dialysis, chemotherapy and surgery, in patients with incurable conditions and without reasonable possibilities of recovery. But the concept does not cover only invasive measures and, in some cases, even the administration of antibiotics should be avoided [3,4]. In sum, the exact classification as therapeutic futility depends essentially on the case, the patient's clinical status and its own personality.

The adequacy of any medical act must be determined by the best judgment of the attending physician, justified in leges artis and in the idea of the greatest good for the patient.

In this evaluation the guiding principle should be the following one: it is not part of the goals of medicine to prolong biological life at any cost, without regard to its quality [8-10].

V. ASSISTED SUICIDE

Assisted suicide is characterised by the fact that death is caused by the person himself, through with the help of a third party. If a person causes his own death this is not a crime, i.e., if the suicide attempt fails he will not be held criminally responsible. But the same is not true when the agent causes the death of another person, even if he acts at that person’s request, or even when the agent simply leaves at his disposal the means necessary to put an end to his life.

One of the more famous cases, even due to the cinema (see the movie “Mar Adentro”), is the one of Ramón Sampedro, a Spanish quadriplegic with his spinal cord severed in 1968. Since then he lived chained to a bed, with no possibility of recovery, without even being able to commit suicide due to his total immobility. This case is extremely complex since Sampedro was not suffering from a fatal disease, not even from physical pain, but "only" from emotional pain [11].

Medically assisted dying for the terminally or hopelessly ill competent adult is generally forbidden around the world, with some exceptions. Even when is not considered an autonomous crime there is no guarantee that the agent will not be prosecuted. In Europe assisted suicide is expressly authorized in The Netherlands, Belgium and Switzerland, but from these three only Switzerland allows the coming of foreigners looking for help to die.

Curiously enough, very recently the British Supreme Court opened the door for a future legislative reform. The case refers to three severely disabled men that asked for a dignified death. In a very welcomed, but disputed (it was taken from 5 to 4), decision the Court stated that the prohibition of assisted suicide in English law violates the right of private life (R (Nicklinson and Lamb) v Ministry of Justice, R (AM) v Director of Public Prosecutions [2014] UKSC 38 (25 June 2014) [12].

VI. ADVANCE DIRECTIVES

In Portugal, Law n. 25/2012, from 16/07, allows each citizen of full age to beforehand express his will in a matter so intimate and sensitive as end of life decisions [4]. The implementation of the decision will be carried out by means of an advance directive, which may take the form of a living will or a Health Care Proxy. A very similar legal solution is also adopted in many European countries and in several north-American states.

Indeed, just as the legal system allows us to leave written documents stipulating the destiny of our assets after death, nowadays the law offers a similar possibility regarding medical treatments. It is recognized to the patient (or future patient) the power to decide if he rejects life support
measures, such as receiving artificial support for vital functions, artificial hydration or blood transfusions. Note that the living will operates, not only as a mechanism to refuse treatments, but also to expressly require them.

Another different option is to grant powers to a proxy - the so-called Health Care Proxy -, who has legitimacy to represent the patient in medical matters exclusively. This representative should be someone of the absolute trust of the person, knowledgeable of his values and beliefs, but not necessarily a relative.

Advance directives do not imply the legalization of euthanasia or assisted suicide. Their aim is simply to leave to each one of us the decision about the medical proceedings that we want or do not want to receive when the process of death is already installed and any measure to be applied will merely briefly postpone the inevitable moment of death, often at the expense of heavy physical and mental suffering and degradation.

It might happen that some of the patient’s decisions conflict with the doctor’s beliefs. Consequently, the doctor maintains the general possibility to appeal to conscientious objection.

The great asset of this kind of legal solutions is, on the one hand, to relieve physicians of such a heavy decision and with so many moral and religious implications; on the other hand, to comply with the fundamental rights of the patient, namely freedom of religion, bodily integrity and the right to personal self-determination on issues essential to human life and human dignity.

VII. THE JURISPRUDENCE OF THE EUROPEAN COURT OF HUMAN RIGHTS

Some of the most celebrated juridical decisions on this regard come from the European Court of Human Rights (ECHR), under the Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) [13-15].

Among the Court’s decisions stands out the Pretty case (Pretty v. The United Kingdom, n. 2346/02, decision from 29 April 2002, ECHR), a well-publicized judicial battle [16]. Diane Pretty was an English woman that gradually was languishing with a severe neurodegenerative disease that would paralyze all the muscles in her body: first the arms and the legs, then the facial muscles (even impeding oral communication) and finally the breathing muscles, leading to her death in a slow and excruciating manner. Conscious of her destination, Diane requested some kind of authorization able to allow her husband to help her to commit suicide, but with the assurance that he would be safe from criminal proceedings. After the denial of this pretension in all English jurisdictions, she appealed to the ECHR.

Diane based her pretension on the following arguments: (a) the right to life also embraces a right not to be forced to live (article 2 ECHR); (b) the destiny that expected her with the progression of the disease violated the protection against inhuman and degrading treatment (article 3 ECHR); (c) the criminal prohibition of assisted suicide violated her sphere of intimate and personal decisions (article 8 ECHR); (d) the prohibition also violated her freedom of conscience, thought and religion, because prevented her to decide according with her personal convictions (article 9 ECHR); the criminalization of assistance to suicide discriminated against those who, like herself, had no chance of committing suicide without external help (article 14 ECHR).

Not surprisingly, the ECHR rejected all these arguments, as it had done previously in similar cases. The main reason is the fact that the ECtHR advocates an understanding of human dignity so protectionist that is unable to respect individual decisions.

According with the ECtHR, article 2 CEDH (“Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law”) does not include within its scope of protection the right not to be alive, but only the right to be alive. This idea is well expressed in an unfortunate quote of the Court in the Pretty decision: “The consistent emphasis in all the cases before the Court has been the obligation of the State to protect life. The Court is not persuaded that “the right to life” guaranteed in Article 2 can be interpreted as involving a negative aspect. While, for example in the context of Article 11 of the Convention, the freedom of association has been found to involve not only a right to join an association but a corresponding right not to be forced to join an association, the Court observes that the notion of a freedom implies some measure of choice as to its exercise”.

The last pronunciation of the ECtHR about end of life decisions refers to the story of Vincent Lambert, a French man that suffered a road accident in 2008, which caused him a severe head injury. As a result he became tetraplegic and today he is totally dependent on artificial nutrition and hydration. In January of 2014 his doctor decided to discontinue all life sustaining measures. This decision was grounded on the French law, the so-called Leonetti’s Act (French law 2005-370 of April 22, 2005), which regulates patient’s rights and end of life matters. The main core of the law is to fight against therapeutic futility. Therefore, it allows the withholding or withdrawal of medical acts deemed to be “useless, disproportionate or having no other effect than solely the artificial preservation of life” [17].

However, and despite the agreement of some of Vincent’s relative, the other part of the family disagreed with that decisions and presented an urgent application looking for an injunction to avoid the withdrawal of medical support. Following a ferocious judicial family battle in the French courts, on 24 June 2014 the Conseil d’Etat - the French superior administrative court - decided that the doctor decision was legitimate in light of French legal order and also consistent with the desire of the patient, expressed before the car accident. However, the ECtHR suspended this decision, in a very unusual proceeding. The final decision from the ECtHR is still to come but the ending is quite
predictable and most probably the ECtHR will maintain the overprotective approach to end of life decisions.

VIII. HUMAN DIGNITY IN THE END OF LIFE

There are two main understanding regarding the value of human dignity [18, 19]: dignity as autonomy and dignity as constraint or limitation. In the first sense dignity walks associated with the idea of the individual as an independent creature, able to determine the direction of his own life; while in the second sense dignity intends to express the intrinsic value of human life, which must be respected and protected from every single attack, including the self disposal of one own life [20]. Whereas in Anglo-Saxon legal order self-determination tends to prevail, in continental European law human dignity, in this ultra protective understanding, takes the lead [21, 22].

The ones sustaining that the prohibition of end of life decisions entails a conflict between human dignity and self-determination should be prepare to impose on someone an obligation to live on behalf of collective interests. Actually, that is what happens in all those cases in which the law denies the help to dye to severe handicapped patients, facing huge physiological and physical pain and living conditions that they find humiliating. This paternalistic protection of the individual negates his freedom of choice and violates the basic core of human rights [23].

The only acceptable meaning of human dignity is the one that accepts the individual in his singularity, respecting his beliefs and his inalienable right to not be alive.

IX. CONCLUSION

The right not to live is the result of a new understanding regarding the right to life, which intends to underline the negative dimension of this right, closely connected with the right to self-determination.

The traditional right to life would mean very little and be very poor if the person could not, in total freedom of mind, decide to stop living whenever the living conditions are so painful, restrictive and humiliating that they go against the principle of human dignity. The right to life cannot simply be understood as a form of physical existence. On the contrary, it involves a whole range of faculties, pleasures and possibilities, all destroyed by some medical conditions that reduce the person to a mere living entity.

The new technological achievements, though able to successfully improve our living conditions, can also extend human presence to a point where is no longer a human live but a mere physical existence. The right not to live aims to confer some dignity to the ones experiencing these existences, by providing them the power to decide when to stop living.

REFERENCES

AUTHOR’S PROFILE

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