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Bioethics and Health Law: the Living Will. Proposal to Create a Living Will Record in Europe

Abstract: In this piece of work, we present a proposal to create a living will record in Europe that will allow people to have the same rights wherever they are.

Therefore, this article will be studied from the bioethics and health law theory.

Keywords: Living will, bioethics, health law, autonomy

The impact of life sciences in the law is becoming clearer and more consequential. Improving quality of life and increased life expectancy brings with it the emergence of new rights and, therefore, the efforts of jurists to establish the necessary legal categories for "naming" these realities that directly affect the protection of human rights and, at the same time, the establishment of mechanisms to ensure the new rights are created.

Just as in the field of ethical philosophy was set up as self-vindication of their rights by the individual against the superior power (religious, national, social ...), in the field of bioethics and in particular in relations doctor-patient autonomy represents a patient's self-assertion against the power (often exorbitant) of the doctor.

Autonomy from a general point of view is the recognition of self-responsible act of every human being has the right to determine their own destiny and personal life, with respect to their own values and world view. Autonomy is the anthropocentric argument that seems to emerge from the secular culture and liberal anti-authoritarian religious ethics and worship the state as the monopoly of legitimate force that imposes moral content.

At the bottom of this concept is the liberal paradigm, hosted at the outset by Stuart Mill, "in which no interest to anyone but him (the individual) independence is absolute. Over himself, over his body and his mind the individual is sovereign. (...) The only thing men can allow individual or collectively to disturb the freedom of action of some of his fellows is to protect itself. The only legitimate reason that a community may have to proceed against one of its members is to prevent harm to others. It is not reason enough of the physical or moral well this guy "and Kant's postulates in the sense of universal legislation will the individual who is capable of proposed goals and meet them.

The autonomy based approach is proposed as one that is not identified without further with the wishes of the agent, but they must pass through the filter "or" filter "of rationality. With this criterion of rationality is not trying to defend a moral theory to be a perfectionist in the state (or a higher court) that imposes a pattern of behavior, but simply that the will as such, "pure", cannot be source of rights, nothing more.

In the present case is clear example of the transformation that is taking place in the final stage of life where it must increasingly aware of the many possibilities that exist when deciding on treatments that may or not submit.

It is the expression of the principle of autonomy characteristic of modernity, where the individual has entered not only his life but also manager of the process of dying. And there at the risk of such a complex technology to take you to be unconscious that give rise to documents that can express their will, commonly known as advance directives (living will).

Living will has been defined as “a document that gives instructions to physicians about certain kinds of health care that an individual would NOT want to undergo. The influence of biotechnology in Law is becoming stronger and has important repercussions. Improving the quality of life and increasing life expectancy implies the emergence of new rights and, therefore, the efforts of jurists to establish the necessary legal categories to “give name“ to these realities that influence the protection of human rights. Additionally, it is necessary to establish pathways to ensure that the new rights are created. We belong to a research group that has been working on decisions at the end of life for several years. Recently the Spanish ministry of Science and innovation is supporting a grant on a project to optimize the information about living will and how to unify the information of the different regions into one national registry. The topic is becoming increasingly important for two reasons:

First, the growing value attached to patient autonomy in health care decision making.

And second, the extraordinary advances in clinical treatments and in life-sustaining technologies, which on one hand may allow physical survival for years, but on the other hand in some circumstances, could be no longer of real benefit for the patient and become futile.

There is a significant number of European Union citizens who are living outside their home state, either on holiday or for work. But the issue here is that many of them choose to live the last years of their life in another country. For example, think of the many people who fix their residence in the Canary Islands, the Balearic Islands in the south of Spain or Italy, Greece and Malta, among others. Therefore, we suggest the creation of a *European Registry* that would gather the living wills of citizens and would be available for the authorities of the

EU countries. In that way, authorities could take into account a person's living will if he or she is in another country within the European Union.

The current situation is the following one: it is not possible to know if a German person who lives in Spain has given or not living wills in his country. Therefore, in the case of a health emergency, this person will be deprived of his/her capacity to decide regarding certain treatments. We propose a European Directive to harmonize the minimum criteria about the living will and an European Registry. Ideally, there should be a European coordinator of the information through the organization of the European Registry of living will record. The role of the coordinator would be to connect the national registry of each Member State to a centralized computer. Therefore, whenever a person in the EU grants a living will, there would be a option to enroll in the European Registry to allow that the data automatically appear in any country of the regardless of their nationality. This would also require the existence of single coordinated software, which should comply with the highest levels of security in terms of data protection to ensure the privacy of the grantors. Nevertheless, a European Registry of living will would require the creation of standards to unify criteria

Since what a person in one country grants as advance directive could not be allowed in another country.

We understand that, at least, the following aspects should be unified:

- A) Who can grant the living will
- B) Contents of the living will record
- C) How to grant the living will
- D) Language
- E) the limits of the Living will record
- F) The need of continuous updates
- G) Conscientious objection
- H) Access to data from the European record and the Protection of the privacy of the subject.

What one needs to think now is: who can grant the living will record? Only adults can do that? What about minors, or emancipated minors?. We should also study the problem of disabled people. Be as it might, we should establish minimum standards to harmonize the existing legislation. It should be discussed if we are talking about care and future treatments of a person's health because that person cannot speak for himself, or if are also talking about the fate of his body. Or if we are talking about personal aspects, accompaniment, spiritual

care, respect for beliefs, home care, etc. The authorities of any Member State should be able to give the living will regardless the nationality of the subject. The requirements and regulations should be age and ability to attend to their personal law as indicated in the internal regulations of each country. Due to the fact that there are several official languages in the European Union, the European registry should include a program for automatic translation to the language chosen by the person who must access the registry. In any case, at least, they should always appear in English and French. It should provide certain cases where the provisions of extravagant living will contain requests which are contrary to law or public policy of a country. It is advisable to introduce legislation that allows regular modification of these Living Will Record's documents. The techniques and medical treatments to change and at some point could be presented as incurable by the time evolution is, by the emergence of effective solutions, or because they change some circumstances. It should be discussed the need to include a general provision guaranteeing the right to conscientious objection of doctors who wanted to express it, as well as the citizen's right to get his living will applied. As mentioned before, access to data and to the living will record should be kept under maximum-security data protection.

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