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Lluís Cabré
María Casado
Jordi Mancebo

End-of-life care in Spain: legal framework

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L. Cabré (✉)
Servei Medicina Intensiva,
Hospital de Barcelona. SCIAS, Diagonal 660, 08034 Barcelona, Spain
e-mail: 10654lcp@comb.es
Tel.: +34-93-2542400
Fax: +34-93-2542402

M. Casado
Observatori de Bioètica i Dret. UB,
Cátedra UNESCO, Barcelona, Spain

J. Mancebo
Servei Medicina Intensiva, Hospital de Sant Pau, Barcelona, Spain

Introduction

Prominent cases affecting care at the end of life in critically ill patients have been reported in several European countries [1, 2]. These cases have fueled a necessary debate regarding the need of having a legal framework to appropriately deal with these issues [3, 4].

In Spain, there is no specific legislation regulating the withdrawal or withholding of treatment in end-of-life care or in critical patients on life support. However, the avoidance of inappropriate prolongation of life and the withdrawal or withholding of life support when the patient desires it or when it is considered futile is considered good clinical practice [5]. This decision takes place in the confidential context of the physician–patient relationship.

A few months ago, a patient who was permanently a ventilator dependent because of a progressive muscle dystrophia, asked for ventilator withdrawal. This patient, who had always complete consciousness to take decisions, was admitted in a hospital owned by the church. The ecclesiastic hierarchy dealt with her petition and decided to transfer the patient to a public hospital, where ventilator support was withdrawn by her responsible physician. Such process is not considered euthanasia but withdrawal of life support. The case was widely commented on the press, but no judiciary process was carried out [6].

The Spanish Society of Intensive and Critical Care and Coronary Units (SEMICYUC) has published guidelines about end-of-life decisions [7]. A recent multicenter study showed that 71% of patients, who died in the ICU because of a multiple organ dysfunction syndrome, had some type of limitation of treatment [8]. Furthermore, the vast majority (over 95%) of critical care departments in Spain is made up of intensivists that have completed the Department of Health's MIR (*médicos internos y residentes*) specialist training in intensive medicine and therefore these departments have also adopted the SEMICYUC's guidelines. In Spain there are publications [9, 10] dealing with different aspects of therapeutic decisions in end-of-life care in the critically ill patients which are covered by diverse authors, including physicians, jurists, philosophers and nurses.

Determining the moment of death

Since 1979, the Spanish legislation on transplantation has listed brain death as a criterion of death [11]. Spain was one of the first countries to accept this scientific criterion as a legal one. The law has evolved and further decrees specifying the requisites for the diagnosis of death have been issued to adapt it to the advances in the field of medical science. The law only specifies that "the death of

a person can be certified after confirmation of the irreversible cessation of cardiorespiratory functions or of the irreversible cessation of encephalic functions". Such certificate is to be signed by three doctors, one of whom has to be a specialist in Neurology. This means that the diagnosis of brain death is determined on clinical grounds (physical exam, EEG, transcranial Doppler, etc.). The law does not require a specific set of criteria to diagnose brain death.

End-of-life care

In a world in which death is usually medicalized, the act of dying generally takes place in a hospital, in a technified and professionalized context that isolates the dying from their usual environment and from their family. These circumstances directly lead to the idea that not everything that can be done should be done and, to the problem of "euthanasia". The Spanish Penal Code [12] defines euthanasia as the termination of somebody's life at his/her demand. Such act (euthanasia) has to be accompanied by an explicit and unequivocal request formulated in the context of a severe disease that otherwise would lead the patient to die or that would generate permanent and unbearable suffering. We acknowledge, however, that it might become necessary to abandon the term "euthanasia" in the ICU context because of its recent historical implications [13]. Care for the dying and protection of the person's dignity during withdrawal of life support in our ICUs should be the main priority in this area.

In Spain, it is extremely unusual to admit patients in the ICU for the sole purpose of providing palliative care. Some hospitals in Spain, however, have palliative care units organized under a similar philosophy to the British system of hospices. In Spain these units are not always available for everyone who might need them and this issue was a subject of a recent judicial process that was commented in a letter to the editor of this journal [14]. In January 2008, the court of justice (Audiencia Provincial de Madrid) gave the final resolution regarding the "Leganés case". The audience did not condemn the physicians previously accused of wrongdoing and they were fully absolved [15]. It is noteworthy that even Recommendation 1,418/99 of the Parliamentary Assembly of the Council of Europe on the protection of the human rights and dignity of the terminally ill and the dying, states that the prolongation of life is not the exclusive aim of medicine.

In our country, issues related with withdrawal of life support (i.e., respiratory, hemodynamic, nutritional, etc.) are not specifically legislated. Informed social debate is not yet generalized and the legislature has not come to any decisions about them. Only ancillary recommendations are available, such as those elaborated by the SEMICYUC [5] and protocols in force in some hospitals that indicate how this problem is to be approached in the framework of the care provided to the public. The main issue here is who must take the decisions at the end of life when the patient is unconscious [16]. In Spain, the law [17] states that such decisions are to be taken by the family (first degree, second degree, etc.) or by a legally appointed surrogate.

Patients with persistent vegetative state raise profound questions for society that must be analyzed and debated. In Spain, this debate has been held among medical specialists (such as intensive care physicians, neurologists, etc.), jurists, bioethicists and the scientific societies [18]. It is essential to bear in mind that PVS refers to a clinical state affecting a person who, as such, is entitled to the full protection of the law and retains his/her fundamental rights, regardless of his/her clinical condition. Numerous constitutional rights come into play as stated in the Spanish Constitution: to physical and moral integrity (Section 15), to ideological and religious freedom (Section 16), to freedom and security (Section 17), to family privacy (Section 18) and to the free development of personality (Section 10.1). Thus, it is a question of applying this exhaustive legal framework to individual cases, keeping in mind that the law is a mean to resolve conflicts in the lives of persons living in society. Nowadays, in Spain, there is no data regarding the magnitude of the persistent vegetative state cases and there is no data on how different treatments (i.e., artificial nutrition, hydration, nursing care, etc.) are implemented.

Guidelines for end-of-life patients

In Spain, there are several different guides for patients and declarations of patient's rights that discuss matters related to end-of-life care [19]. The use of advanced health directives to ensure that the patient's wishes are respected when the patient becomes incapacitated and, as an additional step, the effective promotion of informed consent, has been highly regulated. Numerous autonomous communities also have elaborated their own regulations regarding this matter; for instance, Catalonia was a pioneer in regulating Advanced Health Directives, since January 2001 [17]. All these communities have an official registry. In Catalonia (about 7 million inhabitants), a total of 12,763 advanced health directives had been registered by the end of 2006.

On the other hand, good medical practice guidelines have been elaborated by different scientific societies involved in the process of dying, such as the SEMICYUC [5], the Spanish Society for Palliative Care [20], and the Spanish Society of Neonatology [21]. In addition, the Convenio de Oviedo [22], which ranks as the highest law

in Spain in these issues, also regulates the provision of advanced health directives; in consequence, all Spanish institutions are obliged to follow these principles.

Euthanasia, assisted suicide and the Spanish law

Under Spanish law, the state has no duty to protect life beyond the will of an individual person. Furthermore, the right to dispose of one's own life may be inferred from the right to freedom (Section 1 Spanish Constitution) as a supreme value and from the right to free development of personality (Section 10 Spanish Constitution). Nevertheless, the Constitutional Court has shown a restrictive interpretation on the scope of individual autonomy, and only considers those liberties specifically delineated as such in the Constitution to be constitutional rights.

Article 143 of the Penal Code in force punishes, to different degrees, euthanasia and assisted suicide and diverse ways in which third parties might cooperate in inflicting lesions. This is an apparent contradiction with the Constitution. However, to the best of our knowledge, nobody in Spain has been condemned in a justice court because euthanasia or assisted suicide. The interpretation is that on top of the Penal Code, prevails a higher rank law which is the Spanish Constitution (Section 1 and Section 10). The jurist interpretation of the Spanish Constitution is that this law, unambiguously protects and defends human life, but do not impose any obligation of living against one's personal will when unbearable suffering is present.

Clinical practice

There is currently a generalized consensus that both withholding and withdrawing life support without curative aims represents good medical practice. Likewise, the use of drugs to alleviate suffering that have the concomitant effect of shortening life is considered to be a good medical practice. Actually, limitation of treatment is common in Spanish ICUs [8, 23], and this practice is accepted by the vast majority of the intensive care community.

The deontological codes of the Spanish Medical Colleges have been continuously adapting to changes in the social and legal frameworks, and have come closer and closer to those positions that recognize the need to respect the patient's autonomy. The different updates of the deontological codes of the different medical societies in Spain have broadened the limits of permissiveness in assisting death, while explicitly rejecting futile treatments, since these are unanimously considered to be malpractice. Futile therapy is considered as "inhuman or degrading treatment". On a practical level, daily problems in communication between physicians, patients and family members persist, making decisions about end-of-life care even more difficult [24].

Future

The SEMICYUC, through its working group on planning and organization, has elaborated 120 indicators to measure the quality of care and one of these indicators refers to withholding and withdrawing life support; moreover, this indicator is among those considered to be of fundamental importance [25].

In Spain, several institutions are favorable to an open debate about the decriminalization of euthanasia and to give rise to legislation regulating this process. Up to now, our Parliament, however, is not considering to discuss this issue as has been already done in other European Countries. Along those lines, the Catalan Consultative Committee on Bioethics recommends the decriminalization of euthanasia and assisted suicide for individuals with irreversible terminal conditions that ask for assisted death [26]. Other independent institutions (not necessarily representing the Spanish State position), such as the Observatory on Bioethics and Law at the University of Barcelona, have elaborated documents about euthanasia and about advanced life directives [27]. These documents have led to new declarations along the same lines by the Institut Borja de Bioètica at the Ramon Llull Catholic University [28]. This Jesuit institution, in clear opposition to the official view of the Spanish Church and the Vatican, has also recommended to decriminalize euthanasia in some specific settings and under very precise conditions; diseases in which death is expected to occur within a short time frame, unbearable suffering, explicit patient consent, adequate medical interventions so as to guarantee absence of pain and suffering, ethical committee approval and official notification [29].

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