

## **Advance care planning in Spain. A short national report. Part II**

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### **ABSTRACT**

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**Purpose:** Ethical and legal recognition of patient autonomy and rights is a reality in Spain. Together with informed consent, advance directives and advance care planning have also played a major role in bringing about this situation. This paper aims to provide a description and critical analysis of their ethical and legal framework, concept, grounds, purpose and requirements under Spanish law, and to show that the appropriate way to understand and implement advance directives is to integrate them into the broader process of advance care planning, combining its legal, ethical and clinical dimensions.

**Materials and methods:** Descriptions, arguments and conclusions presented in this paper are based on a

review of legislation, case law and scientific bibliography.

**Conclusions:** Spanish legal norms on advance directives represents a step forward in the consolidation of autonomy as a core of doctor-patient relationship and in the guarantee of patients, healthcare professionals and health institutions' rights and duties. Moreover, it guides professionals and eases decision-making process in healthcare. Finally, it improves the quality, humanisation and justice of Spanish health system.

**Key words:** advance care planning, advance directives, autonomy, clinical decision-making, end-of-life, patient rights, Spain

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## CONTENT

What can the patient decide in his/her advance directives? Article 11.1 Act 41/2002 highlights three distinct statements, which must be completed with the regional and health legislation to arrive at the six statements which constitute the current legal contents of advance directives. In any case, those legal references to the content of advance directives might not be understood as a *numerus clausus* but as an open set, in accordance with the broad scope of autonomy.

### Medical interventions, care and health treatments

Due to the increasing chances of extending life, advance directives (living will) were originally issued to limit healthcare professionals' interventions. Nevertheless, the patient can decide both on the interventions he does not wish to receive and on the interventions and care which he wishes to receive in concrete clinical situations, including the withholding and the withdrawal of life-sustaining treatments as well as decisions on palliative treatment, sedation, comfort and other measures.

### Designation of a proxy

Advance directives can include the designation of a proxy. He plays an important role in the advance care planning process, and should be a trustworthy person, aware of patient's wishes and values. The proxy cannot take decisions on behalf of the patient on situations previously issued in the advance directives document. Otherwise it would imply misunderstanding advance directives and confusing them with surrogate decisions. The function of the appointed proxy is to act as an interlocutor with healthcare professionals helping them to interpret patient's wishes and guaranteeing the respect of values and the compliance of instructions included in the advance directives document [1].

### Personal values, preferences and objectives

Another important support for interpreting advance directives is the patient's expression of his values, preferences, objectives and life prospects [2]. The so-called *values history* provides information on the patient's general stance to life and health, illness, pain and death; his family relationships; his relationships with healthcare professionals; his thoughts on autonomy, independence and self-control; his religious beliefs or personal values; or his preferences on healthcare. Despite the incompetence of the patient at the moment of clinical assistance, his values history can guide decision-making process, eliminate conflicts and reduce the uncertainty and anxiety of those who undertake this task.

It is recommended to communicate the values history to the doctors, to the appointed proxy and to relatives or close friends who will probably accompany the patient during the healthcare process. It should be updated in cases of relevant changes (e.g. death of a close friend or relative, previous experiences of illness, etc.) so that it contains the patient's real and current values. Likewise, in order to being known, implemented

and documented, the values history must be included in the clinical history as a part of the advance care planning process.

### Destiny of the body, organs or tissue

The patient can donate his body for research or for training future healthcare professionals, or simply indicates what he desires for his body after death. Likewise, when death has been confirmed, the patient can donate all or some of his organs and tissues. Despite the fact that Spanish legislation adopts the model of presumed consent in the case of a deceased donor (we are all potential organ donors unless we have an expressed opposition) [3], in practice the family of the deceased are asked for authorisation and their opposition to donation would prevail. Therefore every decision on donation (acceptance or refusal, total or partial) included in the advance directives document states doubtlessly patient's will about it and promotes the respect of his autonomy.

### Use of reproductive material

Health legislation offers a new content to be included in an advance directives document. Concerning the assisted human reproduction, the husband of a woman receiving fertility treatment can decide about the use of his reproductive material within the year following his death [4].

### Obtaining and analysing biological samples

Health legislation provides a sixth content, that refers to the possibility of using the advance directives document to prevent the deceased patient's biological samples from being obtained and analysed after his death [5].

## LIMITS

Article 11.3 Act 41/2002 expressly establishes three limits for applying advance directives, enforcing the healthcare professional to include a reasoned record of the notes relating to it in the patient's clinical history. Moreover, the Autonomous Communities' norms qualify the second of these limits and add, in a questionable manner, another two [6].

### The legal order

This limit aims to reaffirm not taking into account any request for assisted suicide or euthanasia included in a document of advance directives. Both behaviours are criminal offences in Spanish Criminal Code (article 143) [7]. On the other hand, a request to refuse treatment, both withdrawing or withholding life-supporting treatment (incorrectly labelled "passive euthanasia"), is lawful and protected by Spanish legislation (articles 2.4 and 8.5 Act 41/2002, and some regional legal norms: Andalusia, Aragon, Navarre).

### The *lex artis*

The legal criteria to determine the correction and diligence of medical practice is *lex artis*. It is an undetermined and imprecise limit whose meaning changes over time and from one action to another.

Moreover, it is difficult to set as it demands positive determination by law. Interpreting *lex artis* solely from medical or technical criteria, without taking into account patient's wishes and values stated in advance directives, could lead to paternalism and unjustified restrictions of patient's rights [8]. Because of this, instead of *lex artis* or, similarly, good or sound medical practice [9], it has been suggested a new limit instead: contra-indication, i.e. an intervention that the healthcare professional must neither indicate nor carry out even under patient request [10].

### **The lack of correspondence with advance directives statement**

Advance directives can be drawn up in a generic way or in a more specific one. The professional must establish the correspondence between the statements of the advance directives document and the actual situation in which it has to be implemented. This limit to implementing advance directives is at stake when the statement of the document does not match the current situation. Correspondence between previous and current situation must not be understood as an exact match or identity but rather as an analogy, established by the healthcare professional after interpreting patient's will. For this, two contents of advance directives have special significance: the designation of a proxy and the expression of patient's values and objectives.

### **Professional or medical ethics**

Some Autonomous Communities have unfortunately and unjustifiably introduced two additional limits to the application of advance directives. Firstly, *professional ethics* or *medical ethics* [11], a confusing limit which wrongly assumes that ethical criteria of healthcare activity are fixed unilaterally by medical profession and neglects the norms and criteria shared by all, especially those included in the legal regulation on advance directives and patients' rights.

### **Conscientious objection**

Even more objectionable, secondly, is the consideration of the *conscientious objection* as a generic limit to applying advance directives, as it introduces more confusion amongst professionals on the meaning of advance directives and the conscientious objection [12]. On one hand, because the recognition of the conscientious objection does not vary because of the form or time of the patient's expression of his wishes (informed consent or advance directive), but depends on the activity to which the professional claims to object. On the other hand, one cannot recognise the conscientious objection in a generic form but one must specify to what concrete activity one wants to oppose such an objection [13].

## **FORMAL AND PROCEDURAL REQUIREMENTS**

Advance directives must be set down in a written form (articles 11.1 and 11.2 Act 41/2002) [14]. The Autonomous Communities' norms have regulated in great detail the formal and procedural requirements,

establishing two general procedures to issue advance directives (before a notary and before three witnesses) and, in the case of some Autonomous Communities, adding a third procedure (before the person in charge of the Registry of advance directives or corresponding public Administration) [15].

Compliance with formal requirements is a condition of validity and efficacy in advance directives. This *ad solemnitatem* requirement is sound, in order to protect patient's autonomy and rights in such a delicate and relevant matter. Consequently, oral or unsuitably documented expressions are not advance directives but, at the most, relevant indications in surrogate or substituted decision-making.

### **Issuing procedures**

#### ***Before a notary***

The first way to issue an advance directives document is before a notary, a legal practitioner who confers authenticity, veracity and legal force to the acts and declarations made before him. The notary states the authenticity of the advance directives document and the patient's true identity, competence and will as well as the correspondence of the document's content with the patient's wishes. In this case, witnesses are not needed.

#### ***Before three witnesses***

Secondly, the document of advance directives can be issued before three witnesses. Legislation establishes the requirements and causes of incompatibility of witnesses. They must be over 18 and full competent; and at least two of them cannot be in the second level of lineal consanguinity or affinity nor be linked by patrimonial relations [16]. Like the notary, the witnesses' function is to guarantee compliance of the validity of authorisation, that the patient is competent, acts freely without being subject to unlawful influence and that the expression contained in the document corresponds to his wishes with no errors in the declaration.

#### ***Before the person in charge of the Registry of advance directives or the corresponding Administration***

Finally, some Autonomous Communities establish a third procedure before the civil servant or member of the Registry of advance directives or the corresponding Administration, and the latter will check compliance with the minimum legal requirements and contents of the advance directives document presented.

### **The Registry of advance directives**

The National Registry and Autonomous Communities' Registries of advance directives were created to ensure the efficacy of advance directives [17]. Their main objectives are to collect information of advance directives (the existence of the document, the place and date of inscription, the contents) and facilitate healthcare professionals in knowing about the advance directives document and its consultation in the event that it must be applied. In order to guarantee the efficient compliance of its purposes, the Registry acts in accordance with certain basic functioning principles: coordination, interconnection, security and confidentiality.

Registration of advance directives documents must be voluntary and with a merely declarative effect of the document's existence and content, rejecting thus its mandatory and constitutive nature, according to which advance directives would only achieve validity after registration [18]. Registration is not a requirement of validity although it influences the efficacy of advance directives. In this sense, it is highly advisable to register advance directives documents to ensure and to permit the access, knowledge and application of its updated version on the entire national territory.

## VALIDITY AND EFFICACY

Once the advance directives have been issued in the aforementioned manner, and having met the remaining requirements, they are valid with no further requests.

### Renewal, ratification and revocation

For their validity and efficacy Spanish legislation does not demand renewal or ratification. Providing there is no evidence or proof of the contrary, the instructions and wishes included in the advance directives document remain. Nevertheless, a lack of ratification could impact the efficacy of advance directives in some cases (e.g. a considerable length of time has passed and a notable change in conditions or values stated in the advance directives document, contravening the patient's initial purpose). To guarantee its applicability and efficacy, temporal ratification is advised. This will facilitate the interpretation and application of advance directives; it will avoid legal uncertainty to professionals and will strengthen the protection of patient's autonomy and rights. In short, ratification or renewal of advance directives is not nor should be a requirement for its validity. Although this could impact its efficacy, the lack of ratification or renewal must not cause the invalidity or inapplicability of advance directives, for the continuance and respect of the patient's autonomy and will.

What is relevant is revocation, which can be exercised freely and at any time by the patient, just doing so in writing. Revocation *stricto sensu* means the cancellation of the previously issued document and the inexistence of a new one. The faculty of revocation also encompasses the modification, or partial alteration of the document maintaining its validity and effects, and the substitution, or total revocation followed by a new issue of advance directives [19].

### Interpretation and implementation

With regards to its nature, advance directives become effective and applicable once the patient becomes incompetent to express autonomously his own wishes. Until then, the patient's current will and decision prevail over the wishes and decisions stated in the advance directives document.

Healthcare professionals must respect and take into account advance directives because of their ethical and professional obligation to respect patient's

autonomy and rights. They have a categorical duty to know the existence and the content of the advance directives and also the duty to comply with the content, even though this is a *prima facie* duty and not an automatic or *all things considered* duty of application.

Like legal field, medical field requires prudential reasoning which leads to the respect of the patient's autonomy but not to blind or unconditional obedience of every autonomous decision. The patient's advance directives are not an exclusionary reason for the healthcare professional which obliges him to comply with them without balancing and harmonizing the principles, values, duties and rights at stake. Advance directives, often imprecise as it is humanly impossible to accurately and completely forecast future situations, need to be interpreted and contextualised by the healthcare professionals, using the values history and the appointed proxy as support. This interpretative task must go beyond literal and subjective criteria in favour of a teleological interpretation. Only in this way the patient's real will and wishes can be understood and respected, determining their meaning in each concrete case and complying with them or, if necessary, not applying them, where the healthcare professional must state the reasons of non-application of advance directives in medical records.

### Normativity

In this sense, it is important to distinguish two types of normative content in advance directives, with a different form of fulfilment and application. The first one adopts the form of rules, i.e. dilemmatic or all-or-nothing norms (they are either fulfilled or not) which indicate in a direct and definitive manner what one "ought to do": e.g. the decision on organ or tissue donation, or the designation of a certain person as a proxy. In these cases, one must comply with the clearly expressed instruction as it cannot be questioned. Conversely, the second type adopts the form of principles, i.e. norms which aim to obtain or realise in the greatest possible degree a state of affairs, how they "ought to be": e.g. instructions on healthcare and treatments ("*not to withhold or withdraw any life-sustaining measures to prolong my life*"; "*no extraordinary measures to be adopted*") [20]. The lack of precision of these decisions does not eliminate their normativity nor the obligation of the healthcare professionals to respect them, but it demands that the situation and wishes stated by the patient are defined and match real conditions in context and in the moment in which they are to be implemented, which excludes their automatic application and demands interpretation and deliberation for compliance [21].

## OTHER LEGAL ANSWERS ON ADVANCE CARE PLANNING

The failure of advance directives and other similar instruments (living will, do-not-resuscitate orders, powers of attorney) in clinical practice in the USA led to a shift of focus towards advance care planning processes [22,23,24,25,26,27,28]. At the same

time, it encouraged the development of new documents [29,30] that would increase the precision of the meaning of the patient's wishes regarding the care and interventions he or she wishes to receive and would make good some of the deficiencies of advance directives, namely a lack of understanding by the patient of clinical conditions and alternatives; ignorance of a patient's decisions on the part of healthcare professionals; and an inaccurate or mistaken interpretation of a patient's wishes [31]. Although Spain has less experience than the USA in this sphere, it could nevertheless be said that advance directives are not the only legal institution for advance care planning in Spanish legal system.

### Self-guardianship

Almost simultaneously to advance directives, self-guardianship (*autotutela*) was introduced into the state legal system (article 223 Civil Code) [32]. Both institutions share the same purpose: to respect the individual's autonomy to manage his life and health and participate in advance care planning; to widen the scope of autonomous decisions forecasting future incompetence; to improve the decision-making process in the case of incompetent patients, helping them to interpret and apply their instructions and wishes. However, its significance and scope are not identical. Self-guardianship acts on a wider personal area, not limited to health matters, and also on the patrimonial area, banned from advance directives. It allows some decisions of the competent person to forecast future incapacitation and not mere incompetence, which is the case of advance directives. Amongst such decisions is the designation of a guardian, whilst advance directives refer to the possible designation of a proxy. Moreover, the only valid procedure for issuing self-guardianship is a notarial public document unlike the three procedures in advance directives [33].

### Preventive powers of attorney

Another option of advance care planning is preventive powers of attorney, whose aim is the appointment of someone who voluntarily acts when a person's incompetence occurs or worsens. Two types of powers must be highlighted: the *ad cautelam* power of attorney, in the event of future incompetence, which takes effect when this occurs (both incompetence and incapacitation, depending on what has been established), and the power of attorney granted for immediate effect, even in a situation of competence, with continuity and subsistence of effects once incompetence occurs (article 1732 Civil Code) [34]. The granter of power must be in full competence. The proxy can be any individual or legal person and can be designed as guardian or not (separate protection of personal and patrimonial matters: article 236 Civil Code). Its content can be very varied: patrimonial matters (e.g. management and disposal of assets) and some personal matters, amongst which decisions on care and medical treatments or the designation of a proxy, are common. This power does not require a special form but, for the sake of its efficacy, knowledge and publicity,

it is recommended being granted in public document, as the registral publicity of these appointments is limited.

### Life Support Preferences Questionnaire (LSPQ)

The *Life Support Preferences Questionnaire* (LSPQ) [35,36], a clinical tool to improve communication between healthcare professionals and patients (and, when appropriate, their proxies) regarding life support measures, has been validated for use in Spain. This questionnaire provides a brief and easy to understand description of six clinical scenarios referring to different situations, degrees of illness and care needs, about which a patient expresses his opinion. Five of these scenarios refer to the patient him- or herself, whilst the sixth and final one places the person in the position of proxy for a teenage relative who needs dialysis. The LSPQ aims to clarify a patient's preferences for the final stages of life, overcoming the difficulty of reliably and accurately documenting a patient's wishes regarding care and treatment during this period, and improving the identification and interpretation of his or her true will in the clinical decision-making process.

## CONCLUSIONS

Spanish legal norms on advance directives represents a step forward in the consolidation of autonomy as a core of doctor-patient relationship and in the guarantee of patients, healthcare professionals and health institutions' rights and duties. Moreover, it guides professionals and eases decision-making process in healthcare. Finally, it improves the quality, humanisation and justice of our health system.

Nevertheless, despite the comprehensive legal regulation of advance directives in Spain, there are unresolved challenges for advance care planning. Some challenges, linked to the legal system, must be resolved by jurists, in particular by the legislator, completing the normative development. Apart from the necessary homogenisation of national and regional legal norms, normative errors need to be corrected, ambiguities in terminology need to be clarified and the vagueness of some concepts needs to be dealt with. Other challenges, linked to healthcare, must be dealt by healthcare professionals and institutions, trusting in Law as an instrument which improves healthcare relationships and favour its reception and suitable use by means of appropriate knowledge, respect and application [37-43]. Both movements require moving beyond advance directives and promoting the more comprehensive advance care planning (Advance planning processes not only improve end-of-life care and patient and relative satisfaction, but also reduce healthcare costs [44-46].

### Conflicts of interest

None.

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2. This content is not included in Act 41/2002, but it is included in some Autonomous Communities' norms (e.g. Andalusia, Aragon, Balearics, Basque Country, Canaries, Extremadura, La Rioja, Navarre).
3. Act 30/1979, 27 October, on organ extraction and transplantation (article 5); Royal Decree 1723/2012, 28 December, regulating the activity of obtaining, clinical use and territorial co-ordination of human organs for transplantation and establishing quality and security requirements (article 9); Royal Decree 1301/2006, 10 November, establishing the quality and safety norms for donation, obtaining, evaluation, process, preservation, storage and distribution of human cells and tissues and the co-ordination norms and functioning for their use in humans (article 8).
4. Article 9.2 Act 14/2006, 26 May, on techniques of assisted human reproduction: "Despite what is stated in the previous section, the husband can give his consent for his reproductive material being used to inseminate his wife in the 12 months following his death, in the document which is referred to in article 6.3, in a public document, in a testament or in an advance directives document. [...]".
5. Article 48.2, first paragraph Act 14/2007, 3 July, on biomedical research: "Samples of deceased people can be obtained and analysed in health area, providing it is always for health protection, unless the deceased has expressly forbidden this when alive and thus this is proved. With this aim the advance directives documents and, when not available, the opinions of the closest relatives to the deceased will be consulted".
6. Couceiro Vidal A. Las directivas anticipadas en España: contenido, límites y aplicaciones clínicas. *Revista de Calidad Asistencial*. 2007;22(4):213-22, 217-21.
7. Article 143 Criminal Code. 1. Anyone who induces another to commit suicide shall be punished by imprisonment from four to eight years. 2. The punishment of imprisonment from two to five years shall be imposed for cooperating with necessary acts to the suicide of a person. 3. When cooperation amounts to implementing the person's death shall be punished by imprisonment from six to ten years. 4. Anyone who causes or actively cooperates through necessary and direct acts to the death of another, when there is an express, serious and unequivocal request, in the case where the victim suffers a serious illness which will necessarily lead to his death or which causes serious and permanent suffering which is difficult to withstand, shall be punished to imprisonment in one or two degrees lower than those mentioned in numbers 2 and 3 of this article.
8. See Judgements of Supreme Court (Civil Section) 830/1997, of 2 October; 1132/2006, of 15 November; 1267/2006, of 5 December. See Judgements of Supreme Court (Administrative Section) of 16 January 2007; of 1 February 2008; of 22 October 2009; of 25 March 2010; of 13 November 2012. See also Judgement of Constitutional Court 37/2011, of 28 March.
9. Aragon, Cantabria, Catalonia, La Rioja, Valencia.
10. Basque Country, La Rioja.
11. Aragon (medical ethics), Madrid (professional ethics).
12. Balearics, Cantabria, Extremadura, La Rioja, Madrid, Murcia, Valencia.
13. Azucena Couceiro, José Antonio Seoane, Pablo Hernando, "La objeción de conciencia en el ámbito clínico. Propuesta para un uso apropiado (I)", 26/3 *Revista de Calidad Asistencial* (2011), pp. 188-193.
14. The patient can draw up and document his or her advance directives in the way that he or she wants. He or she can follow one of the existing guideline models or forms. Some Autonomous Communities (e.g. Andalusia) requires that an official form or model is completed.
15. Andalusia, Basque Country, Castile and Leon, La Rioja.
16. In some cases (e.g. Cantabria, La Rioja) the incompatibility is stricter.
17. Article 11.5 Act 41/2002 and Royal Decree 124/2007, 2 February.
18. In some Autonomous Communities (e.g. Andalusia, Cantabria) the registration of advance directives is constitutive and mandatory.
19. Appendix of Royal Decree 124/2007, 2 February.
20. A clinically oriented example in Couceiro A, Pandiella A. La EPOC: un paradigma para uso de directivas anticipadas y la planificación anticipada de decisiones. *Archivos de Bronconeumología*. 2010; 46(6): 325-31, 328.
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  29. See the document Five Wishes® [cited 2015 Jan. 30]. Available from <http://www.agingwithdignity.org/five-wishes.php>.
  30. The *Physician Orders for Life-Sustaining Treatment* (POLST). (Available from <http://www.polst.org/>). POLST is the document's original name (Oregon, USA) and the one by which it is most commonly known, but there are others with the same purpose and content, for example POST (Physician Orders for Scope of Treatment: West Virginia), COLST (Clinical Orders for Life Sustaining Treatment: Vermont) o MOLST (Medical Orders for Life-Sustaining Treatment: New York).
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  32. Reformed by Act 41/2003, 18 November.
  33. With a similar purpose but less detail, article 4.2.f) Act 39/2006, 14 December, to promote personal autonomy and care of people in situation of dependence, recognises the right to decide, when he/she is competent, on the protection of his/her person and property for the case of becoming incompetent.
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