

End of life decisions in the case of incompetent and terminally ill children under Spanish Law

Gonzalo Arruego*

ABSTRACT: This article addresses the Spanish constitutional and legal framework of end of life decisions especially with regard to incompetent and terminally ill children.

KEYWORDS: Fundamental rights to life and to personal integrity; informed consent; terminally ill patients; incompetent patients; minor patients.

SUMMARY: 1. Introduction – 2. A matter of fundamental rights – 3. The Spanish legal framework on informed consent – 3.1. The general provisions concerning informed consent and the right to refuse or to withdraw medical treatment – 3.2. The right to refuse medical treatment of the terminally ill and/or of the patients in the process of dying – 4. Informed consent in the case of minor and adult incompetent patients. 4.1. Fundamental rights, informed consent, minority and legal incapacity – 4.2. Who consents and how in the case of minors and incompetent patients? The “best interest” approach – 5. Final remarks: the facts of the so called “Andrea case”.

1. Introduction¹

Though the social debate on euthanasia has been permanently present in Spain with more or less intensity since the early nineties², it has been sparked again in the recent years though not in its broad sense but, to some extent, in a more restricted but more sophisticated manner. This process seems coherent with the recent evolution of the Spanish society³ and of the Spanish medical law framework, despite the fact that assisted suicide is a still a criminal offence⁴. In this sense, since the Inmaculada Echeverría case in late 2006 it seems pacifically accepted that under Spanish Law an adult and sound patient can refuse any medical treatment even at the cost of

* Member of the Public Law Department and the Research Group AGUDEMA (financed by the Aragonese Government) of the University of Zaragoza (Spain). Mail: garruego@unizar.es. Essay selected by the Steering Committee among submissions to the Call for papers on End of Life issues.

¹ This research is part of the Research Project FRONTIUSFUND (DER2014-52817-P) and was also possible thanks to the Grant PR2015-00334, both financed by the Spanish Ministry of Education, Culture and Sports.

The Spanish Constitutional Court decisions are quoted indicating STC-ATC (Spanish Constitutional Court Sentence-Spanish Constitutional Court Edict)/Reference number of the Sentence-Edict/Year/Paragraph

² Especially due to the Ramón Sampedro case.

³ With regard to the Spanish society's attitudes on end of life decisions see the CIS' studies 2451 (2002) and 2803 (2009).

⁴ According to article 143.4 of the Spanish Criminal Code, “Whoever causes or actively co-operates in the necessary, direct acts causing the death of another, at the specific, unequivocal request of that person, in the event of the victim suffering a serious disease that would unavoidable lead to death, or that causes permanent suffering that is hard to bear, shall be punished with a punishment lower by one or two degrees to those described in Sections 2 and 3 of this article”; Sections 2 and 3 respectively punish “whoever cooperates in the necessary acts for a person to commit suicide” and “co-operation to reach the point of death ensuing”.

his/her life⁵. Actually, many Autonomous Communities have passed the so called “Death with dignity acts” enshrining, among others, the rights of the terminally ill to palliative care and to refuse any life support measures⁶.

But, what happens when we are not dealing with the petition of a competent patient but with the request of the representatives of an incompetent one? Or, more specifically, what happens in the case of the plea of the parents of a terminally ill child to withdraw the life-support measures that maintain him/her alive? Is the legal framework exactly the same in the case of sound patients and in the case of incompetent patients and children? Is such a demand lawful?

These, and other questions, were raised by the case of Andrea, a 12 year old Galician girl suffering from a rare and irreversible neuro degenerative disease whose symptoms were evident since she was eight month old. Her parents, due to the serious clinical condition of her daughter, plead for the withdrawal of her life support treatment.

Departing from the questions arose by the so called “Andrea case”, the aim of the following pages is to examine the Spanish legal framework concerning end of life decisions especially in the case of incompetent patients.

Does Spanish Law entitle patients to refuse any medical treatment regardless the consequences and the circumstances? What’s the nature of that faculty? Is the legal framework similar in the case of competent and incompetent patients? And, in the case of the latter, who decides and according to which principles?

To answer all these questions, this work opens with the exploration of the constitutional nature of patient’s autonomy and then examines the general legal framework concerning informed consent and its limits. It then moves to the case of minors and incompetent adult patients from both the constitutional and the legal perspective, adding the question of the rights of the terminally ill and those in the process of dying. It finally closes with some remarks on the so called “Andrea case”.

2. A matter of fundamental rights

It is now commonly accepted that patient’s autonomy and its main manifestation, informed consent, are a matter of fundamental rights. Consenting a medical intervention or refusing or withdrawing

⁵ By the end of 2006, Inmaculada Echeverría, a 51-year-old resident of Granada who had been bedridden and on a respirator for the last 20 years of her life as a consequence of a degenerative disease (muscular dystrophy), demanded to have her respirator turned off. Though her petition did not finally reach the Courts, two different reports, a first one issued by the Ethics Committee of the Government of Andalucía and a second one by the High Consultative Body of the Government of Andalucía, supported her request. She finally died on March 14th 2007 when her life support was switched off by the doctors; see ARRUEGO, G., *Life-support treatment refusal as a fundamental right: the case of Inmaculada Echeverría*, in CASONATO, C., PICIOCCHI, C., VERONESI, P. (eds.), *Forum Biodiritto 2008. Percorsi a confronto: Inizio vita, fine vita e altri problema*, Padova, 2009.

⁶ The most recent ones being the Law 1/2015 of the Autonomous Community of the Canary Island, the Law 4/2015 of the Autonomous Community of the Balear Islands, the Law 5/2015 of the Autonomous Community of Galicia and the Law 11/2016 of the Autonomous Community of the Basque Country. As it will be shown below, the question is whether this new legal framework really adds something new in terms of patient’s autonomy that could not be directly inferred from the fundamental rights guaranteed by the Spanish Constitution and the provisions contained in the Law 41/2002, *Basic Law on the Autonomy of the Patient and the Rights and Obligations with Regard to Clinical Information and Documentation*.

medical treatment are considered the expression of the exercise of the fundamental right to personal integrity regardless of the motivations of the patient⁷. This is expressly proclaimed by article 3 of the *Charter of fundamental rights of the European Union*⁸.

The fundamental right to life plays a different role in this context as its content is alien to the recognition of patient's autonomy. Actually, it has been usually used to establish restrictions to that autonomy.

This is mainly due to its consideration as a prohibition whose object is human life in a purely biological sense and which imposes positive protective obligations on the State. These features are reinforced by its consideration as "the logical and the ontological *prius*", the "essential" fundamental right "without which the other rights and freedoms constitutionally protected would simply not exist"⁹. From this perspective, the right is understood in negative terms as a purely defensive right with no positive content. As a consequence, its conception as a freedom conferring a right to die is rejected¹⁰. However, that does not mean that taking one's own life is unlawful: as it is not forbidden by the law, it would be a mere manifestation of *agere licere*, though never a right. Furthermore, the recognition of such a right would violate the core of the fundamental right to life as it is constitutionally proclaimed¹¹.

⁷ Motivations that can make his/her decision the expression of other fundamental rights too; for example the freedoms of ideology or religion, SSTC 48/1996/2, 120/1990/8 or 154/2002/9.

⁸ Under the consecration of the "Right to the integrity of the person", the Charter proclaims that "In the fields of medicine and biology, the following must be respected in particular (...) the free and informed consent of the person concerned, according to the procedures laid down by law". As to the Spanish Law, the right to personal integrity is proclaimed in article 15 of the Spanish Constitution along with the fundamental right to life: "Everyone has the right to life and to physical and moral integrity, and under no circumstances may be subjected to torture or to inhuman or degrading punishment or treatment. Death penalty is hereby abolished, except as provided for by military criminal law in times of war". According to the European Court of Human Rights' Case Law, the fundamental right to personal integrity is protected under article 8 of the European Convention of Human Rights.

⁹ STC 53/1985/3; in a similar way, the European Court of Human Rights has affirmed in *Pretty vs. The United Kingdom* (2002), that "The Court's case-law accords pre-eminence to Article 2 as one of the most fundamental provisions of the Convention (...). It safeguards the right to life, without which enjoyment of any of the other rights and freedoms in the Convention is rendered nugatory" (§ 37). Even its considerations on the existing relationship between the refusal to a medical treatment and the rights guaranteed by article 8 of the Convention, depart from the assertion that in no way they can be understood as contradictory with "the principle of sanctity of life protected under the Convention" (§ 65).

¹⁰ STC 120/1990/7. Similarly, the European Court of Human Rights has stated that "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 (...) It is unconcerned with issues to do with the quality of living or what a person chooses to do with his or her life. To the extent that these aspects are recognised as so fundamental to the human condition that they require protection from State interference, they may be reflected in the rights guaranteed by other Articles of the Convention, or in other international human rights instruments. Article 2 cannot, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life", *Pretty vs. The United Kingdom* (2002) (§ 39).

¹¹ STC 120/1990/7.

This doctrine has forced to find another constitutional basis for the principle of patient's autonomy and the progressive recognition of a space of self-determination concerning one's own body and health.

Not by chance, this basis has been found in the fundamental right to personal integrity, whose object is, precisely, the human body and the psyche. It is true, however, that the constitutional doctrine on the object and content of the fundamental right to personal integrity is to some extent parallel to the one on the fundamental right to life¹². But being this true, the fundamental right to personal integrity has an additional dimension of the utmost importance in the medical context.

As with the fundamental right to life, physical and psychological integrity are conceived in strict terms excluding again any subjective qualitative consideration¹³. Analogous to the fundamental right to life, the right to personal integrity enjoys a negative or defensive nature but, in this case, with a double perspective. On the one hand, it protects the individual from any attack or threat against his body and psyche. On the other, it proscribes any un-consented intervention in them¹⁴. Within the medical framework, precisely here lies the constitutional basis of the patient's informed consent.

In the words of the Spanish Constitutional Court, "The patient's consent to any intervention is inherent, among others, to his fundamental right to physical integrity, to his right to forbid any unconsented intervention in his body. It is a self-determination right which entitles the patient to freely decide about the therapeutic procedures and medical interventions, choosing, consenting, refusing or withdrawing them. This is precisely the most relevant manifestation of the fundamental right in the medical context: the faculty to freely decide between consenting a medical intervention or refusing it (...) Yet, for that right to be fully exercised, the patient must be previously given the adequate information"¹⁵.

This means that when a patient gives his/her consent to any medical intervention he/she is exercising his/her fundamental right to physical and psychological integrity regardless whether or not it can be considered a manifestation of other fundamental rights too. And, as a consequence, that any medical intervention carried out against or without the patient's consent violates the fundamental right to personal integrity unless it has a constitutional justification¹⁶.

¹² Actually, the Spanish Constitutional Court usually refers simultaneously and indistinctly to both of them.

¹³ In the case of "moral integrity", this understanding can be derived, among others, from SSTC 53/1985, 221/2002 or 162/2007.

¹⁴ "(...) the fundamental right to physical and moral integrity protects the person's inviolability not only against any action intended to harm her body or spirit, but also against any un-consented intervention in them", STC 120/1990/8. In the first place, the fundamental right to physical and psychological integrity entitles the individual to react against any action which causes, or is intended to cause, any physical or psychological harm. This means that, likely to the fundamental right to life, there is no need of an effective harm to consider that the fundamental right has been violated: any active or omissive behaviour which creates a risk of harm transgresses the fundamental right too. However, and once accepted that not any risk poses a threat to the fundamental right, the question is to determine its intensity in order to consider that it has been infringed.

¹⁵ STC 37/2011/5.

¹⁶ "The fundamental right is compromised when a medical treatment is imposed against the patient's will, whose refusal can be based on many different motives", STC 120/1990/8; "The fundamental right to personal integrity prohibits any medical intervention contrary to the patient's will, regardless the reasons adduced", STC 48/1996/2; this doctrine was reinforced by the STC 154/2002/9: "The relevant question is the sole treatment refusal regardless its causes. Beyond the religious beliefs which motivated the minor's refusal to the medical

It has to be stressed that, though this second dimension of the content of the fundamental right *de facto* implies certain self-determination capacity with relation to one's own body, this is mainly as a consequence of the prohibition of any interference with the object of the right without the individual's consent. Therefore, from a constitutional perspective and according to this doctrine, patient's autonomy is not strictly the result of a truly positive self-determination power with regard to her life and body, but the effect of a defensive right which prescribes the previous person's assent once she has been given the adequate information¹⁷. It seems then curious that, despite the fact that informed consent is built on the concept of autonomy, which undoubtedly has liberty resonances, its constitutional shelter is provided by a mainly reactive fundamental right; a situation especially evident in the case of those not being able to consent.

3. The Spanish legal framework on informed consent

3.1. The general provisions concerning informed consent and the right to refuse or to withdraw medical treatment

Due to the territorial structure of the Spanish State, the legal framework of patient's autonomy is constituted by a complex set of norms. The core regulation is contained in the Law 41/2002, *Basic Law on the Autonomy of the Patient and the Rights and Obligations with Regard to Clinical Information and Documentation*. This norm is applicable to the whole Spanish territory and was elaborated as a consequence of the obligations assumed by the Spanish State through the ratification of the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*¹⁸. The norm has to be completed with the legal provisions adopted by the different Autonomous Communities. In the case of the Autonomous Community of Galicia and for the purposes of this study, the Law 3/2001, May 28th, *on informed consent and medical records of the Autonomous Community of Galicia* and the Law 3/2015, June 26th, *on the rights and dignity of the terminally ill persons*¹⁹.

One of the main principles inspiring the Basic Law 41/2002 is the patient's autonomy, a principle expressed, among others, in the general rule of the necessity to obtain his free and informed consent prior to any intervention in his health and, subsequently, his rights to withdraw that consent at any

treatment, and without denying its importance as manifestations of the fundamental right to freedom of religion, it has to be highlighted that the opposition to any intervention in his body was the expression of a self-determination right whose object is the human body in its double physical and psychological dimension; in other words, the fundamental right to personal integrity (article 15 of the Constitution); "In the sphere of medical treatment, the refusal to accept a particular treatment might, inevitably, lead to a fatal outcome, yet the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention", *Pretty vs. The United Kingdom* (2002) (§ 63).

¹⁷ The inexistence of this positive self-determination power is evident when reading the STC 215/1994/2 and the Spanish Criminal Code.

¹⁸ Signed in Oviedo April 4th 1997, the Convention entered into force in Spain January the 1st 2000.

¹⁹ There is a current trend in Spanish Law to regulate in different Laws the general rights of the patients and the rights of those patients terminally ill and in the process of dying. On these matters see PRESNO, M. A. (Coord.), *Autonomía personal, cuidados paliativos y derecho a la vida*, Oviedo, 2011.

moment, to choose among the existing medical alternatives and to refuse the medical treatment. As established by article 2, “every intervention in the health field may only be carried out after the person concerned has given free and informed consent”. After having received the appropriate information, the person “has the right to freely choose among the different existing medical alternatives” and “the right to refuse the medical treatment”²⁰.

There are basically two situations where the principle of patient’s autonomy is excepted and medical treatment is provided in the absence or against the person’s will: when public health is compromised and in the so called “life emergency situations”. Both have to be always interpreted bearing in mind that, as exceptions or restrictions to the fundamental right to personal integrity, they are subject to strict scrutiny²¹.

According to article 9.2 of the Basic Law 41/2002, the strictly indispensable medical interventions can be carried out without the need to obtain the previous patient’s consent when, according to the law, there is a risk for the public health²² and when “the physical or psychological integrity of the patient is at a serious and immediate risk and it is not possible to obtain his authorisation. In this case, and if due to the circumstances it is possible, the doctors will consult the patient’s relatives or those emotionally tied to him”²³.

Concerning the interpretation of the latter, it seems now pacifically accepted that when a sound patient refuses or withdraws a medical treatment this can naturally lead to his death; in other words, it

²⁰ According to article 8, “Every intervention in the health of the patient requires his previous free consent after having received the information prescribed by article 4 and having evaluated the different existing alternatives”. As a general rule, consent will be oral, however, it will be written in the following cases: surgical procedures, invasive procedures and every procedure which carries any possible risk or notorious and foreseeable negative consequences in the patient’s health. The patient has the right to freely withdraw his consent at any time in written. The Oviedo Convention establishes in its article 5 that “An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time”.

²¹ According to reiterated Spanish Constitutional Court’s case law, the concrete imposition of a limit to a fundamental right is only legitimate when it satisfies different formal and substantive constitutional requirements. Concerning the former, the Court demands that, as a general rule, the restriction has to be imposed by a reasoned judicial decision in the light of a specific law. With regard to the latter, the aim of the restriction has to be the preservation of another constitutional right or constitutional interest, it has to be established fitting the requirements of the proportionality principle and, whatever the result of the limitation is, it can never violate the dignity of the person as a human being.

According to article 26.1 of the Oviedo Convention, “no restrictions shall be placed on the exercise of the rights and protective provisions contained in this Convention other than such as are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others”.

²² See the Organic Law 3/1986, *on especial measures concerning the public health*.

²³ Similar provisions are contained in articles 4 and 11.2 of the Law 3/2001, May 28th, *on informed consent and medical records of the Autonomous Community of Galicia*. According to article 8 of the *Convention on Human Rights and Biomedicine*, “when because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned”.

seems accepted that the sole preservation of the patient's life does not legitimate anymore the imposition of a medical treatment against his will²⁴.

In this sense, the jurisprudence of the Spanish Constitutional Court has apparently evolved from considering that a Court order imposing a blood transfusion to a Jehovah Witness is constitutionally legitimate²⁵, to first establishing that the situation is probably different when the patient is under the public authorities jurisdiction (prisoners in hunger strike) than when he is a free citizen²⁶, to finally accepting that to refuse a medical treatment is a legitimate exercise of the fundamental right to personal integrity which might have a "fatal outcome"²⁷.

In other words, when the refusal or the withdrawal of a medical treatment does not pose any threat to the public health nor to any third rights or interests constitutionally protected, there is no constitutional justification to impose it; not even in the so called "life emergency situations"²⁸.

There are many constitutional arguments to defend so and even without conceiving the fundamental rights to life and personal integrity as liberties²⁹. The crucial question is to determine whether the

²⁴ Former article 10.6.c) of the *General Health Law* of 1986 also imposed the obligation to obtain the patient's consent before any medical intervention. However, this general rule was excepted "in emergency situations when there is a risk of irreversible harm or death". This clause, interpreted under the light of the Spanish Constitutional Court's doctrine on the protection of the fundamental right to life, legitimized the imposition of a medical treatment against the patient's will when her life or health were at serious risk.

²⁵ ATC 369/1984.

²⁶ STC 120/1990. The Constitutional Court stated that, according to article 25.2 of the Constitution, imprisonment gives birth to a complex of rights and duties between the State and the prisoners that legitimates the imposition of restrictions to the fundamental rights of the latter, not applicable to free citizens. Within this framework, the Court asserted that interpreted in the light of article 25.2 of the Constitution, the duty of the authorities to preserve the life, health and personal integrity of the convicts, imposed by article 3.4 of the Organic Law on the Penitentiary System, legitimated the restriction to the fundamental right to personal integrity consisting in the coercive medical assistance to those prisoners whose lives were in serious and immediate risk; a restriction that might not be applicable to free citizens. However, and despite those assertions, the final central argument to justify the imposition of the force feeding of the inmates was the preservation of human life "as one of the superior values of the Spanish legal order". In this sense, it rests unclear whether in the Court's mind it was really possible to draw such a distinction between inmates and free citizens. It has to be borne in mind that the argument concerning the preservation of human life as a constitutional value, and specially the way the Court built his reasoning upon it, has a universal nature.

²⁷ SSTC 154/2002 and 37/2011.

²⁸ See ARRUEGO, G., *La naturaleza constitucional de la asistencia sanitaria no consentida y los denominados supuestos de 'urgencia vital'*, *Revista Española de Derecho Constitucional*, n. 82, 2008 and *Vida, integridad personal y nuevos escenarios de la biomedicina*, Granada, 2011.

²⁹ In the context of this doctrinal discussion, to uphold that in the Spanish constitutional system the fundamental right to life includes a fundamental right to die, it is usual to allege the interpretation of article 15 of the Constitution in the light of liberty as one of the "superior values of the Spanish legal order" (article 1.1), the free development of the personality as the "foundation of political order and social peace" (article 10.1) or the fundamental rights to freedom of ideology and religion (article 16) and to personal privacy (article 18.1). These considerations would lead to the understanding of the fundamental rights to life and to personal integrity as guaranteeing a sphere of "conscious and responsible self-determination" (STC 53/1985/8) with no other restrictions than those arising from the preservation of third parties' fundamental rights and interest constitutionally protected.

In the context of the European Court of Human Rights' Case Law: "As the Court has had previous occasion to remark, the concept of 'private life' is a broad term not susceptible to exhaustive definition. It covers the physical and psychological integrity of a person (...) It can sometimes embrace aspects of an individual's physical and

constitutional system of fundamental rights tolerates such a restriction of the individual's rights when his decision does not impinge on third parties' constitutionally protected rights or interests. This would finally lead to the identification of a constitutionally guaranteed space of *agere licere* which would exclude any public interference.

To sum up, no restrictions can be posed to the decision of a patient rejecting a medical treatment even at the cost of his life when no other interests are at stake. In this sense, the so called "life emergency situations" are not restrictions to the principle of the patient's autonomy but, more properly, mere exceptions. That is to say, these kind of legal provisions confront those situations where, due to the concurring factual and personal circumstances, it is necessary to carry out an intervention in the person's health to preserve her personal integrity or even her life, but she cannot express her assent or refusal³⁰. In conclusion, this legal provision does not authorise to carry out a medical intervention against the free will of a sound patient but, precisely, in its absence.

3.2. The right to refuse medical treatment of the terminally ill and/or of the patients in the process of dying

As stated above, one of the current trends in Spanish medical Law is the passing by many autonomous communities of specific Laws on the rights of the terminally ill and of those patients who are in the process of dying. The so called "dead with dignity bills".

Among other provisions, such as for example those concerning therapeutic obstinacy or the right to receive palliative care, these norms contain specific clauses on patient's autonomy and, specially, on his/her right to refuse and withdraw medical treatment³¹.

social identity (...) Elements such as, for example, gender identification, name and sexual orientation and sexual life fall within the personal sphere protected by Article 8 (...) Article 8 also protects a right to personal development, and the right to establish and develop relationships with other human beings and the outside world (...) Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees"; "The Court would observe that the ability to conduct one's life in a manner of one's own choosing may also include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned. The extent to which a State can use compulsory powers or the criminal law to protect people from the consequences of their chosen lifestyle has long been a topic of moral and jurisprudential discussion, the fact that the interference is often viewed as trespassing on the private and personal sphere adding to the vigour of the debate. However, even where the conduct poses a danger to health or, arguably, where it is of a life-threatening nature, the case-law of the Convention institutions has regarded the State's imposition of compulsory or criminal measures as impinging on the private life of the applicant within the meaning of Article 8 § 1 and requiring justification in terms of the second paragraph", *Pretty vs. The United Kingdom* (2002) §§ 61 and 62; "(...) the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention", *Haas v. Switzerland* (2011) § 51.

³⁰ It has to be highlighted that in these cases the possibility of obtaining the patient's informed consent is excluded by its own nature. This is the reason why article 9.2.b) of the Basic Law 41/2002 does not use the term consent but authorisation.

³¹ See ARRUEGO, G., *El derecho del paciente a rechazar el tratamiento en la nueva normativa 'sobre el proceso de la muerte'*, PRESNO, M. A., (Coord.), *Autonomía personal, cuidados paliativos y derecho a la vida*, Oviedo, 2011.

Concerning the Autonomous Community of Galicia, this is the case of the recent Law 3/2015, June 26th, *on the rights and dignity of the terminally ill persons*.

It is true, however, that with regard to the patient's autonomy article 14.3 of the Law 8/2008, June 10th, *on Health Care in the Autonomous Community of Galicia*, already recognized the right of the terminally ill patients "to refuse the life support treatments which simply prolong their suffering". Yet, the Law 3/2015 establishes a more precise regulation and, after recognizing in its article 7.3 the patient's right to refuse the medical treatment even when his life is at stake, it recognizes in its article 10 the rights to refuse surgical procedures, artificial feeding, artificial hydration, resuscitation and life support treatments³².

The problem, however, is how the scope of these provisions is defined; an issue which raises a general question from the point of view of patient's autonomy: whether this new legal framework really adds something not already deducible from the Constitution, the Basic Law 41/2002 and well established and accepted medical practices and, if so, whether the new regulation is then coherent with the constitutional and general legal framework as interpreted above.

It has to be noted that the scope of this legal provisions is especially reduced. As the Law 3/2015 asserts, it refers to the terminally ill patients who face the process of dying and all the decisions involved³³. And the refusal to the medical intervention is recognized in the context of "extraordinary and disproportionate measures which cause excessive pain and suffering" or which "prolong agony or artificially maintain life in extreme poor conditions"³⁴.

In fact, though the Preamble of the Law asserts that the compromise of the Legal Order in preserving life is not absolute, as considerations concerning the quality of life have to be taken into account, the affirmation has to be understood in the context of the affirmation of the "inevitability of death" and of the asseveration that "every human life reaches a point where the reasonable and useful thing to do is avoiding pain and suffering as far as it is possible and not prolonging life at any price".

From this point of view, it seems that more than concerned with the quality of life, the legislator is actually concerned with the quality of dying, which obviously is not exactly the same.

In other words, the problem is that these legal provisions may suggest that the rights to refuse or to withdraw a medical treatment at one's own life cost or to refuse or withdraw life support measures or artificial hydration or feeding are recognized not to every patient, but only to those who are terminally ill.

However, though it is true that these new norms increase legal certainty both for terminally ill patients and doctors, they should not be interpreted as misleading to the conclusion that patients are entitled with those rights only in such dramatic conditions. Actually, note that the only coherent solution with such line of reasoning would be that the only life-saving or maintaining treatment that can be refused or withdrawn is that one that, according to the *lex artis*, can be considered futile.

³² The wording of article 10.1 is obviously improvable, as it literally recognizes not the right to refuse, but the right of the patient to "express his will concerning the refusal".

³³ Article 3.8 defines the terminally ill patients as those "who suffer an advance, progressive and incurable disease, with a short life prognosis and with multifactorial, changing and serious symptoms causing intense physical and psychological suffering to the patient and her close ones".

³⁴ Articles 10.1 and 10.3.

This is not, of course, the current constitutional and legal framework of patient's autonomy as described *supra*.

4. Informed consent in the case of minor and adult incompetent patients

4.1. Fundamental rights, informed consent, minority and legal incapacity

As described above, informed consent is a matter of fundamental rights; mostly, but eventually not only, the manifestation of the fundamental right to personal integrity. And, as the international and national legal framework shows and the Spanish Constitutional Court has vigorously asserted, minors and incompetent adults "have exactly the same rights as the rest of the citizenry"³⁵.

This means that with regard to minors and incompetent adults the crucial question is not whether they enjoy fundamental rights, but the way they can exercise them.

The current majoritarian view is that, though some faculties are impossible to be exercised by means of others or "to represent"³⁶, the crucial point is the possibility of realization or satisfaction of the interest safeguarded by the fundamental right in the best interest of the minor or the incompetent adult³⁷.

Due to the lack of constitutional provisions regarding the capacity to exercise a fundamental right, the regulation concerning minors contained in article 162 of the Spanish Civil Code has been applied analogically. According to it, legal representation is excluded with regard to the exercise of rights of personality when the holder is mature enough to perform them by him/herself, though the intervention of the parents/tutor is acknowledged as part of their caring duties³⁸. As it will be immedi-

³⁵ STC 215/1994/1; "(...) according to international treaties, the wording of the Constitution (everyone) and as the legislation shows, minors are holders of fundamental rights and as they mature the need for the intervention of their representatives gradually diminishes", STC 154/2002/9.

³⁶ No one can, for example, make an opinion or an idea on my behalf or exercise my liberty of movement.

³⁷ Denying the possibility of distinguishing between the enjoyment and the exercise of a fundamental right "has the consequence of undermining its protection and effectiveness (...) the question is not the real identification between the holder of the right and the person exercising it on his/her behalf, but their functional identification (...). The existence of a Constitutional mandate to protect minors and incompetent adults justifies the possibility of exercising a fundamental right through a representative". In this sense, though sometimes the interest protected by the fundamental right can only be implemented through the direct exercise by his/her holder, "there are situations where that interest can be protected and realized through the exercise of the fundamental right by a third party if the holder lacks the legal or natural capacity to exercise the right", ALÁEZ, B., *Minoría de edad y derechos fundamentales*, Madrid, 2003, pp. 110, 113 and 115; see also BASTIDA, F., VILLAVARDE, I., REQUEJO, P., PRESNO, M. A., ALÁEZ, B., SARASOLA, I., *Teoría General de los Derechos Fundamentales en la CE de 1978*, Madrid, 2012. As the Spanish Constitutional Court has explained, precisely in the medical context, excluding from representation the exercise of the fundamental rights would lead to the unacceptable consequence that, for example, no medical intervention, even a saving life one, could ever be performed in incompetent patients as they are unable to consent, STC 215/1994/4. This discussion had more sense in the context of the now repealed former wording of article 162.1 CC, which excluded from representation those acts "relating to rights of personality".

³⁸ Though fundamental rights and rights of the personality are not equivalent expressions, as there are fundamental rights which are not rights of the personality and vice versa, "due to the fact that there is no norm regulating the exercise of fundamental rights by the under aged, it seems plausible to apply article 162 CC (...) both fundamental rights and rights of the personality face a similar problem: protecting basic interests of the indi-

ately shown, these are the guidelines of the regulation of informed consent in the Spanish legislation as, not by chance, both the Civil Code and the Basic Law 41/2002 were reformed concerning these issues by the Law 26/2015, July 28th, *on the modification of the system for the protection of infants and adolescents*.

The capacity to consent a medical intervention is a matter of natural capacity valued case by case by the doctors and, as to the Spanish law, it is legally presumed at the age of 16 or emancipation³⁹. In this sense, and in the case of minors, it is commonly accepted that as the minor grows his/her maturity is progressively recognised by the Law in connection, among others, with the nature and scope of the decision that has to be made⁴⁰. That is to say, the scrutiny will be stricter depending on the nature of the medical intervention to the extent that, in some cases, the general rule according to which majority is reached at the age of 18 still applies⁴¹.

Of course, the problem with natural capacity is that it is a far less objective and certain criterion, though far less rigid too, than establishing a certain age from which full capacity is legally enjoyed. This is an especially acute problem, above all when certain collectives, such as doctors, are charged with the responsibility of valuing it in such a sensitive and peculiar context as the medical one. Unsurprisingly, and despite the fact that the current regulation is coherent with the majoritarian trend on minority/incapacity and fundamental rights, changes have been proposed. For example, returning

vidual that imply transcendental values. This is the reason why it is important to establish to what extent the representatives can impose their views in such delicate matters", DíEZ-PICAZO, L. M^a., *Sistema de derechos fundamentales*, Madrid, 2008, pp. 145-146.

³⁹ With regard to the necessary information that has to be provided prior to consent and regulating consent itself, articles 5 and 9 of the Basic Law 41/2002 establish that doctors are the ones who value if the patient lacks the capacity to make decisions or due to his physical or psychological condition cannot understand his/her situation. Despite the acknowledgement that there are different legal systems concerning incapacity, the fact that in the medical context we are speaking of natural capacity explains, among other reasons, the provisions of the Oviedo Convention establishing that incompetent adults have to be involved as far as possible in the authorization procedure or that the opinion of the minor will be given increasing relevance as he/she is more mature. Actually, the Convention's *Explanatory Report* concludes in the case of minors that depending on the nature of the intervention and the maturity of the minor, her/his consent could be necessary in order to carry the intervention.

⁴⁰ It is a common place pointing out that it is not the same consenting to a minor cure than consenting to a transplant. As the Spanish Constitutional Court has established, it is true that minors see their capacity progressively recognised by the Law as they mature, but this cannot automatically lead to the assumption that minors have the right to refuse a medical treatment at the cost of their lives, as this will depend on the minor's capacity "to fully understand and assume the consequences of his decision", STC 154/2002. Though the affirmations contained in the Court's decision might seem contradictory, as in some passages it seems to directly assert that such a capacity cannot be recognised to minors and in others it seems to link that possibility to their maturity, probably this is due to the fact that capacity has to be examined under the perspective of the decision under scrutiny. As the Court remarks, "the minor exercised his rights to freedom of religion and to personal integrity but we lack enough evidence to conclude that the minor, 13 year old, was mature enough to make and assume such a vital decision", STC 154/2002/9.

Coherently with the International Legal framework, articles 2 and 9 of the Organic Law 1/1996, January 15, *on the Legal Protection of Minors* establish that the restrictions to the minor's capacity have to be strictly interpreted and that he/she has the right to his/her opinion to be progressively taken into account as he/she matures.

⁴¹ For example, to make a living will (article 11 of the Basic Law 41/2002), to participate in clinical trials or in the context of assisted reproductive techniques (article 9.5 of the Basic Law 41/2002).

to the criterion that as a general rule capacity is presumed at a certain age, though rigid, provides with certainty especially to the medical practitioners who, it should not be forgiven, are potentially subject to liability⁴².

4.2. Who consents and how in the case of minors and incompetent patients? The “best interest” approach

It has been a matter of discussion whether it is possible to properly speak of consent and representation with regard to those incapable of consenting by themselves. In this sense, and as suggested above, the possibility of implementing the interest protected by the right whose exercise is under discussion in the benefit of its holder seems to be the crucial idea.

Actually, when referring to those incapable to consent the Oviedo Convention does not use the term “consent” but the term “authorization”; and let’s not forget either that it speaks in its article 6 about the “Protection of persons not able to consent”⁴³. In the case of minors and adults who according to the Law lack the capacity to consent, this will be given by his or her representative or a person or body provided for by the law⁴⁴.

Under the Spanish legislation the general rule is that consent is given by the representative of the patient or, in its absence, by the patient’s close ones. According to article 9.3 of the Basic Law 41/2002, consent is given by the legal representative of the patient basically in three situations⁴⁵.

The first one is when the doctor appreciates that the patient lacks the capacity to make decisions or due to his physical or psychological condition cannot understand his situation. In this case, if the patient does not have a legal representative, which is the usual scenario, consent will be given by his/her close ones. This provision poses the problem of its indeterminacy with regard to who has the responsibility of authorising the intervention⁴⁶.

⁴² “Maturity is a less objective concept and, therefore, the legislative should have established any procedure to judicially determine capacity in order to not to leave its appraisal to other collectives, such as doctors, who should not be charged with this responsibility”, ALÁEZ, B., *op. cit.*, p. 155; “It is true that the age criterion may seem arbitrary and fetishistic (...) It may seem odd that one goes to bed one night being a minor and wakes up the following morning being mature enough to decide every aspect of his life. But this is so in many different situations: speed limits, taxes, deadlines (...) Legal certainty demands it. Think, for example, if suffrage were to be recognized based on maturity regardless the age”, DE LORA, P., *Autonomía personal, intervención médica y sujetos incapaces*, *Enrahonar*, n. 40/41, 2008, pp. 135 and 136. And of course, we should not forget the peculiarities of the medical context and the point of view of the medical profession; as Civeira reminds us, there is a need for flexibility and informality which is present in the current legal regulation, but recurring to collective bodies or to the Courts is sometimes impossible if not a bureaucratic burden that doctors should not bear, CIVEIRA, E., *Consentimiento por representación: cuestiones problemáticas en medicina crítica*, in *Consentimiento por representación*, Barcelona, 2010.

⁴³ It is true, however, that its *Explanatory Report* uses the term consent.

⁴⁴ Article 6.2 and 3 of the Oviedo Convention.

⁴⁵ As explained above, the regulation was recently reformed and, though having solved some interpretative problems and contradictions, others still remain.

⁴⁶ Who are the close ones? In the case of relatives, up to which degree? Are there any gradation or preference criteria? Some Autonomous Communities have established a more precise regulation when implementing the Basic Law 41/2002 in the absence of legal representative of the patient; for example, and in the case of the Autonomous Community of Galicia, article 6.1 a) of the Law 3/2001, May 28th, *on informed consent and medical records of the Autonomous Community of Galicia* establishes that preference will be given to the spouse or to

The second is when the patient has been legally declared incompetent.

Finally, the third case is that of the minors who are emotionally or intellectually incapable of understanding the scope of the intervention. In this case consent will be given by their representative after having heard his/her opinion as prescribed by article 9 of the Organic Law 1/1996, January 15, *on the Legal Protection of Minors*⁴⁷.

It has to be noted that this regulation could be perfectly characterised as redundant, because if capacity is a fact valued by the medical staff regardless age or legal capacity, the first provision would cover all the different possible case scenarios.

But precisely with regard to minors, the last reform of the Law has added a fourth situation: consent must be given by the legal representative of the minor after hearing his/her opinion and taking it into account, when the doctors consider that the action poses a serious threat to the life or health of the minor⁴⁸. That is to say, in these cases the general rule according to which capacity is presumed at the age of 16 or by emancipation does not apply, as the general rule that majority is acquired at the age of 18 will be applicable.

As explained above, this was introduced by the Law 26/2015, July 28th, *on the modification of the system for the protection of infants and adolescents*, following the criteria established by the Director of Public Prosecutions in the Circular 1/2012. According to the Circular, the Constitution establishes that majority is acquired at the age of 18. Therefore, and according to article 39.3 CE, minors are until that age under the protection of the State. As a consequence, any life or health threatening decision taken by the minors or their representatives has to be dismissed in order to preserve their future autonomy⁴⁹.

This new legal framework poses the question of whether some of the provisions contained in the Galician Law 3/2015, which were worded according to the then into force version of the Basic Law 41/2002 and which concern 16 year old and emancipated minors, have been rendered partially ineffective just a month after they came into effect. Actually, article 13.3 states in its second paragraph

the unmarried couple; in its absence to the closest relatives and within the same grade to those taking care of the patient and in its absence to the older ones. As to the Law 3/2015, June 26th, *on the rights and dignity of the terminally ill persons*, its article 5.2 determines that consent will be given by the spouse or the unmarried couple who lives with the patient, by the person who lives with the patient or takes care of him or by the relatives up to the fourth degree of consanguinity.

⁴⁷ As stated in article 12.1 of the *United Nations Convention on the Rights of the Child*, "State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child".

⁴⁸ Article 9.4 of the Basic Law 41/2002.

⁴⁹ The origins of these criteria can to some extent be traced back to the STC 154/2002, though as shown above a different reading of the Spanish Constitutional ruling is possible. Previously, in such cases the decision still apparently belonged to the minor, though the opinion of his legal representatives had to be heard and taken into account. This norm immediately raised serious criticism among its first reviewers mainly due to three reasons: its obscurity, the disclosure of confidential information concerning competent patients that it implied and its apparent inconsistency with other provisions, for example those regulating the living will, according to which capacity was acquired at the general majority age of 18; see, among many others, ROMEO, S., *Un nuevo marco jurídico-sanitario: la Ley 41/2002, de 14 de noviembre, sobre derechos de los pacientes*, *La Ley*, n. 1, 2003.

that “emancipated and 16 year old minors have the right to refuse and withdraw informed consent and the proposed medical procedures in the same terms as adults”⁵⁰. It has to be noted that, as described above, we are talking about a Law which entitles the patient with such rights as refusing or withdrawing life support treatment or artificial feeding or hydration⁵¹.

The criterion according to which the representative has to consent to an intervention in the name of an incompetent patient is the “best interest” of the patient; a criterion which is the guiding principle of the international and national legal framework on the protection of minors⁵².

In this sense, article 6 of the Oviedo Convention establishes that the authorization to carry an intervention in an incompetent person’s health can only be given “for his or her direct benefit” and its withdrawal “in the best interest of the person concerned”⁵³. Similarly, the Basic Law 41/2002 states

⁵⁰ Of course, the improvable wording of the Law poses similar problems as the previous version of the Basic Law 41/2002. For example, after entitling emancipated and 16 year old minors with the same rights as adults, the Law asserts that the parents, tutor or legal representative will be informed and their opinion will be taken into account: What does exactly the provision “their opinion will be taken into account” mean? Besides the fact that this implies the disclosure of confidential medical information concerning a competent patient, if the decision belongs to the 16 year old or emancipated patient himself, it is difficult to understand the meaning of the norm beyond the implication of the parents, tutor or legal representative in a process, the informed consent, along with the doctors and the patient.

⁵¹ In this context, the Law 3/2015 establishes that in the case of minors consent will be given by their representatives, as in the case of incompetent terminally ill patients with regard to the decisions relating life support treatment unless they have no representative, in which case the decision will be taken by the spouse or the unmarried couple who lives with the patient, by the person who lives with the patient or takes care of him or by the relatives up to the fourth degree of consanguinity (articles 13.2 and 10.6). Apparently, incompetent patients are not entitled with the right to manifest their will concerning “the refusal of surgical procedures, artificial feeding and hydration and resuscitation when they are extraordinary or disproportionate and produce extreme pain and/or suffering”, proclaimed in article 10.1; however, this provision has to be interpreted in a context where the right to take decisions concerning the medical interventions in the dying process, the right to refuse any medical intervention though it may pose a risk to the patient’s life and the right to express consent by representation are recognized (articles 7.2, 7.3 and 7.4), and where, as a consequence, incompetent terminally ill patients are entitled to refuse life support measures through their representatives.

⁵² Among other international instruments and national legislation, article 3.1 of the *United Nations Convention on the Rights of the Child*: “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration”; article 24.2 of the *Charter of Fundamental Rights of the European Union*: “In all actions relating to children, whether taken by public authorities or private institutions, the child’s best interests must be a primary consideration”; article 2.1 of the Organic Law 1/1996, January 15, *on the Legal Protection of Minors*: “Every minor has the right to his/her best interest to be considered the main priority in every decision and action, public or private, which concerns him/her. The best interest of the minor will be the supreme criterion in the application of the Law and in the adoption of every decision by the public or private institutions, the Courts and the Legislative, even over any other legitimate competing interest”. As the Constitutional Court has observed, precisely in the medical context, “(...) the fundamental rights of the children cannot be totally abandoned to the discretion of their representatives and the State has the obligation under article 39 of the Constitution to assure that the decisions taken by the representatives are always in the child’s best interest and not in any other interest”, STC 154/2002/9; see also, concerning incompetent adults, STC 215/1994/2.

⁵³ Except in the cases of research and removal of regenerative tissue, which are subject to the requirements expressed in articles 17 and 20 of the Convention. Remember that, very expressively, article 6 the Convention speaks about “Protection of persons not able to consent”.

that the criterion according to which representatives have to decide is “always the most beneficial to the life and health of the patient”⁵⁴.

Leaving aside incompetent patients who were once competent and therefore the question of the eventual existence of previously expressed wishes⁵⁵, it is possible to infer that under Spanish Law and in the medical context the best interest is basically defined in what we could call “objective terms” according to the current *Lex artis*, yet becoming doctors the guarantors that decisions are made accordingly⁵⁶. In the case of minors this understanding is especially reinforced, as the first guiding principle according to Spanish Law and to the jurisprudence of the Spanish Supreme Court in order to determine the minors’ best interest, is the protection of their fundamental right to life and the guarantee of their survival⁵⁷.

This is the reason why, for example, when regulating these situations the Oviedo Convention’s *Explanatory Report* stresses, on the one hand, that doctors have the duty to act in the patient’s benefit as part of their professional standard and, therefore, to protect the patient against those decisions not taken in his/her interest through the adequate recourse procedures established by the Law⁵⁸. And, on the other hand, recognizes that “while a person capable of giving consent to an intervention has the right to withdraw that consent freely, even if this appears to be contrary to the person’s interest, the same right must not apply to an authorization given for an intervention on another person”⁵⁹.

The same applies to the Basic Law 41/2002, which not only establishes that those decisions contrary to the patient’s best interest must be brought before the Courts directly or through the Public Prosecutor, but also that “in emergency cases where it is not possible to wait to the Court’s decision, doctors will perform the necessary procedures to safeguard the patient’s life and health”⁶⁰. Finally, the same can be inferred from the doctrine of the Spanish Constitutional Court⁶¹.

⁵⁴ Article 9.6. On the comparison of the regulation of these issues in the complex Spanish legal framework see LORDA, P. S. and BARRIO, I. M., *¿Quién puede decidir por mí?*, *Calidad Asistencial*, 19 (7), 2004 and *Criterios éticos para las decisiones sanitarias al final de la vida de las personas*, *Revista Española de Salud Pública*, n. 4, 2006.

⁵⁵ Apart from the general provisions contained in the Basic Law 41/2002 and the Galician Laws 3/2001 and 12/2013, articles 10.2 and 10.3 of the Law 5/2015 establish, on the one hand, that every person can express at any moment, even at the moment of admittance to hospital, her rejection to life support treatments which might unnecessarily prolong her agony and artificially maintain her life in poor conditions; and, on the other hand, the right to refuse through a living will future extraordinary and disproportionate surgical procedures, artificial feeding and hydration and resuscitation.

⁵⁶ As De Lora explains, except obviously in the case of previously competent patients who have expressed their views especially through living wills, “the concept of best interest commits us to an objective perspective of the different elements which benefit or worsen the wellbeing of the individual and where his will is obviously disregarded”, DE LORA, P., *op. cit.*, p. 128.

⁵⁷ Article 2.2 a) of the Organic Law 1/1996, January 15, *on the Legal Protection of Minors* and STS 565/2009, among others.

⁵⁸ Paragraph 48.

⁵⁹ Paragraphs 44, 48 and 49.

⁶⁰ Article 9.6 second paragraph.

⁶¹ “(...) the Court order authorising the blood transfusion in order to save the child’s life is constitutionally irreproachable, as life is one of the superior values of the Spanish legal order (...) and the fundamental right to life has a positive protective content which prevents its interpretation as a liberty conferring a right to die. To sum up, the decision to end one’s own of life is not a fundamental right but a mere manifestation of the general

It has to be noted that within this framework not only doctors have a prominent role with their duties and responsibilities notably enhanced, as stated above, but also that this minimizes the possible scope of the representative's decision to the different medical alternatives offered by them, when not to the only medical alternative proposed. That is to say, the decision is prefigured by the health care professionals if not materially taken by them though formally adopted by the legal representative of the patient⁶². Furthermore, it has to be noted that in the context of a democratic and plural society, the "best interest" principle poses the danger of leading to the imposition of majoritarian visions over minorities⁶³.

But the definition of the best interest of the patient and the *Lex artis* itself are subject to the evolution of the socio-cultural values; values which sometimes find express legal recognition⁶⁴.

In this sense, and especially under certain circumstances, the best interest of the patient may be defined beyond the preservation of his/her life and health. This is the case, at least, of terminally ill patients. In this context, the legal concerns about the quality of living the last stages of one's own life become crucial and can lead, precisely, to decide that it is in the patient's best interest to withdraw or not to initiate a medical procedure or to carry those that though ease the pain and suffering shorten his/her life expectancy. As the Preamble of the Law 3/2015 states, the interest of the Law in preserving the patient's life is not absolute and has to be balanced against quality of life considerations, because "every human life reaches a point where the reasonable and useful thing to do is avoiding pain and suffering as far as it is possible and not prolonging life at any price".

principle of liberty, as it is not forbidden by the law, but it cannot be agreed that a minor enjoys such a capacity without any limitation", STC 154/2002/12.

⁶² As the Director of Public Prosecutor's Circular 1/2012 expressly states, the solution in these situations "is the irrelevance of the minors will directly expressed or the decision taken by their representatives when they are contrary to the medical opinion posing a serious risk to the life or to the health of the minor"; note, once again, that this Circular is the basis of the current regulation contained in the Basic Law 41/2002.

⁶³ Concerning the exercise of fundamental rights on behalf of others see DÍEZ-PICAZO, L. M^a, *op. cit.*, pp. 147-148 and GÓMEZ, A. J., *Titularidad de derechos fundamentales*, in ARAGÓN, M. (dir.), *Temas básicos de derecho constitucional*, Madrid, 2011, T. III, p. 45. All these concerns are central in the work of ELLISTON, S., *The best interest of the child in healthcare*, Oxon, 2007. In her opinion, the best interest approach should be substituted by the criterion according to which "the view of parents of what it's right for their children should normally be respected unless they are likely to place them at an unacceptable risk". Of course, the question of how to define the concept of "unacceptable risk" still remains; a concept that according to the author should be determined by recurring to the harm principle and the concept of reasonableness.

⁶⁴ As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research explained in 1983, the "best interests standard" is defined "by reference to more objective" and "societally shared criteria. Thus the best interests standard does not rest on the value of self-determination but solely on protection of patients' welfare"; concerning infants, the Commission estates that "In most circumstances, people agree on whether a proposed course of therapy is in a patient's best interests. Even with seriously ill newborns, quite often there is no issue-either a particular therapy plainly offers net benefits or no effective therapy is available. Sometimes, however, the right outcome will be unclear because the child's 'best interests' are difficult to assess. The Commission believes that decision making will be improved if an attempt is made to decide which of three situations applies in a particular case-(1) a treatment is available that would clearly benefit the infant, (2) all treatment is expected to be futile, or (3) the probable benefits to an infant from different choices are quite uncertain", PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *Deciding to Forego Life-Sustaining Treatment*, Washington, 1983, pp. 135 and 217.

5. Final remarks: the facts of the so called “Andrea case”

Andrea was born on December 12th 2002 suffering from a rare and irreversible neuro degenerative disease whose symptoms became evident at the age of eight months⁶⁵. In September 2014, when she was almost 12 year old, her clinical condition began to worsen and in June 9th 2015 she was finally hospitalized due to a decrease in the platelet levels in her blood (thrombocytopenia) that caused her considerable undernourishment and the rejection of artificial feeding.

Due to the severe deterioration of her health and following their wish of a dignified death for their daughter, her parents asked for the life support measures (artificial hydration and feeding) to be withdrawn. However, the medical staff refused alleging compliance with the Spanish medical legislation and that in no case the situation could be characterized as “futile treatment”.

The case did not only spark the social debate on euthanasia again in recent years, but had political consequences when the Secretary of Health of the Government of Galicia was immediately dismissed from her post after having backed the doctors position stating that the parents’ plea was “active euthanasia”.

The parents decided to take the case to the Courts, which had already authorized in July at the Hospital’s request to continue with the procedures decided by the paediatricians with the goal of “diminishing as much as possible the child’s suffering with respect to her personal dignity”. However, the Court’s decision made clear not only the necessity of regularly valuing the clinical condition of Andrea, but also that the opinion of the Bioethics Committee of the Autonomous Community of Galicia, though of not binding nature, had to be taken into account.

On September 14th 2015 the Committee supported the parents claim recommending the withdrawal of the life support treatment and the adoption of palliative measures.

Under these circumstances the doctors finally changed their opinion and accepted the parent’s wishes. Though they justified their new position on the rapid deterioration of Andrea’s health, it has been claimed that both the new political circumstances in the light of the recent dismissal of the regional Secretary of Health and the desire to avoid an unfavourable court ruling, played a key role in their change of attitude and proved that their initial position was not based on medical reasons⁶⁶.

Doctors finally removed from Andrea the feeding tube and sedated her while maintaining minimum hydration. The child died four days later on October 9th 2015.

⁶⁵ She was noticed to be unable to manipulate objects with her hands and to sit up and having stopped babbling.

⁶⁶ “Terminally ill Galician girl Andrea dies after four days off life support”, *El Pais*, October 9th 2015, http://elpais.com/elpais/2015/10/09/inenglish/1444390475_894081.html (last consulted July 15th 2016).