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Conflict between children's autonomy and protection in healthcare. Comparative study between Spanish and Belgian Law[1]

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Abstract

This paper addresses the autonomy of children and adolescents in healthcare decisions, focusing on those ones that might entail a risk to the child's life or health, especially when a medical intervention is rejected. In these cases, a conflict between the recognition of the autonomy of the child and his or her protection arises, and the different legal systems solve it in different ways. This study examines this issue from a comparative perspective between the Belgian and the Spanish Law, taking into account that the latter was rewritten in 2015 to leave out all underage patients' decisions that could constitute a risk for their life or health.

Keywords

informed consent - children's autonomy - parental authority - refusal of treatment by adolescents - surrogate decision making - children's best interest.

1 Introduction

This paper considers a classic topic in Health Law: children's autonomy to accept or refuse a medical intervention, because despite the attention devoted to this issue, it remains a problematic topic, especially when it refers to an adolescent's refusal to accept lifesaving treatment.

All legal systems accept that, until a person reaches certain age, he or she is not able to exercise his or her rights with full legal validity and is subject to parental authority. Parents must take care and protect their children, and for that purpose, they will be able to make decisions about their children's life. But it is also a fact that children progressively acquire the capacities to be able to understand the importance and consequences of the acts concerning their own lives, and therefore to be able to make decisions on their own. Accordingly, while they grow up there is an increasing tension between their submission to parental authority until the majority of age and their evolving capacities. To resolve this tension, most legal systems have implemented solutions that consist either in indicating ages in which the minor can engage in certain acts on his or her own behalf, or allowing certain acts when the minor is capable to understand the consequences, therefore revoking parental authority in those cases.

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This problematic manifests clearly in the healthcare field, because medical interventions affect the personal sphere of the child, his or her own body, so it seems accepted that his or her preferences must be heard and that certain grade of autonomy must be granted. The legal systems must face a delicate balance between recognizing the autonomy of children and adolescents in this field, revoking parental representation, on one hand, and protecting their interests and rights, on the other one. Underage patients' decisions about health issues can take serious negative consequences in their future life, and some kind of supervision might seem reasonable.

This balance between recognizing the decision-making capacity of the children in healthcare and ensuring their protection changes from one legal system to another. As an example, we will confront how Spanish and Belgium Law have regulated this issue. This comparison is interesting and thought-provoking because the starting point in both legal systems (as it is in other European countries) is the same: the minors are subject to parental authority, but both systems also recognise that, depending on their age and intellectual development, they are allowed to perform certain acts on their own, despite this minor status, especially when the act concerned involves the child's personal sphere. The Laws relating to patient's rights were passed in both Spain and in Belgium in 2002, and are significantly influenced by the Convention on Human Rights and Biomedicine (Oviedo, 4 April 1997), so they have several points in common. However, the two Laws differ considerably with regard to recognition of the capacity of minors, to the extent that according to Belgian Law, a child who is able to reasonably appreciate his or her interests can exercise his or her patient's rights autonomously, including refusal of a medical intervention, while under Spanish Law (after some legal changes approved in 2015), his or her autonomy is restricted, depending on the importance of the treatment, to ensure the protection of his or her future life and health condition.

2 The general incapacity of minors to exercise their rights. Exceptions

Both in Spain and in Belgium, a person reaches adulthood at the age of 18,[2] and from that precise moment, he or she is able to act with full legal validity.[3] Before that age, the child or adolescent is in principle unable to exercise his or her rights, and subject to parental authority (or the equivalent institution if the parents cannot exercise it).[4] This parental authority is not actually considered a right of the parents, but as what it is known in both legal systems as a "right-function":[5] a set of prerogatives that are conferred on parents simply in order to fulfill their obligations to provide the child with the living conditions necessary for his or her complete development. Parents, therefore, need to make decisions about their children's life, under their parental authority, but they will always be bound by the children's best interest.

Anyway, as children grow up, it is accepted that their capacities evolve, and this means a tension with their submission to parental authority until the majority of age[6], which is

[2] Article 12 of the Spanish Constitution, Article 315 of the Spanish Civil Code (from now on, SCC); Article 388 of the Belgium Civil Code (from now on, BCC).

[3] Article 322 SCC; Article 488 BCC.

[4] Article 154 SCC; Article 372 BCC.

[5] M. C. Gete-Alonso, J. Solé Resina, *Filiación y potestad parental* (Valencia: Tirant Lo Blanch, 2014), pp. 129-130. Y. H. Leleu, *Droit des Personnes et des familles* (Bruxelles: Éditions Larcier, 2016), p. 681. A. Nottet, "Mineurs et droits personnels", *Revue trimestrielle de droit familial* (1) (2010), p. 19.

[6] In Spain this tension is apparent in the contrast between parents' obligation to provide their children with assistance of every kind while they are still under age (Article 39 of the Spanish Constitution) and the

solved indicating other ages in which the minor can engage in certain acts on his or her own behalf, revoking parental authority in those cases.[7]

In the particular field of rights relating to personality, there is a tendency to recognise the minor's autonomy, not according to certain predetermined ages, but depending on their own maturity. Article 162 of the Spanish Civil Code excludes the exercise of parental authority in some cases, and the most important exception is for acts related to the rights of the personality, which the child, in accordance with his or her maturity, may perform by him or herself. This provision, along with Article 2.1.II of Organic Law 1/1996, on legal protection of children and adolescents, which rules the restrictive interpretation of the limits to the exercise of rights by children, have provided an argument to affirm the autonomy of the minor in the field of his or her rights of personality.[8] As long as a minor is found to be capable of understanding the circumstances and consequences of certain act, he or she will be able to exercise his or her right autonomously, regardless of his or her parents' will or opinion. Legal representation in this field has been traditionally considered impossible, because it concerns the individual's most private and intimate rights.[9] The same rule has been established in Belgian Law. [10]

However, this rule has been called into question since the 2015 legal reforms in Spain concerning children and adolescents. Effectively, a second subparagraph has been added to Article 162.1º of the Spanish Civil Code, such that now, after stating that the parental authority is excluded in acts relating to the rights of personality that the minor is able to perform on his or her own behalf, according to his or her maturity, it is stipulated that the parents will nevertheless "intervene" in these cases by virtue of their care and assistance duties. It is claimed that the purpose of this addition is to reinforce the parents' intervention over their son or daughter's decision,[11] even if he or she is considered mature (and therefore capable of making his or her own decisions), but in our opinion the content and extension of this parental intervention is not very clear. In fact, this redrafting seems to be strongly motivated by demands to restrict the (alleged) extensive autonomy granted

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fundamental right of dignity (Article 10 of the Spanish Constitution), which ensures the free development of the personality.

In Belgium, Article 22 (bis) of the Constitution, added in December 2008, states that every child has the right to moral, physical, mental and sexual integrity and to express himself or herself on any issue concerning him or her, and his or her opinion must be considered in view of his or her age and judgment. In all actions concerning children, the best interests of the child shall be a primary consideration. Similar provisions are contained in the Spain's Organic Law 1/1996 of 15 January on legal protection of children and adolescents (Article 2) and in Article 154 of the Spanish Civil Code.

[7] See, for the Spanish Law, the list of acts indicated by M.A. Parra Lucán, "Minoría de edad", in: M.C. Gete-Alonso, M.C. Calera (dir.), *Tratado de derecho de la persona física*, T. I, (Cizur Menor: Civitas-Thomson Reuters, 2013), pp. 604-607. For the Belgium Law, see Leleu, *supra* note 5, pp. 277-278.

[8] M.C. García Garnica, *El ejercicio de los derechos de la personalidad del menor no emancipado* (Cizur Menor, Aranzadi, 2004), pp. 78-79.

[9] *Ibid*, p. 46. M.A. Parra Lucán, "La capacidad del paciente para prestar válido consentimiento. El confuso panorama legislativo español", *Aranzadi Civil* (2003), p. 8.

[10] M. Aboaf, "L'incapacitédu mineur: un équilibre délicat entre autonomie et protection", in: H. Preumont, I. Stevens (coord.), *Les jeunes et le droit. Approche plusidisciplinaire*, (Limal: Anthemis, 2017), p. 110. Leleu, *supra* note 5, p. 276. However, Nottet points out that the rule of the child's incapacity still applies (Art. 372 BCC) and as such it is useful for the exceptions to this incapacity to be stipulated in an explicit law. Nottet, *supra* note 5, p. 39.

[11] M.J. García Alguacil, "Injerencia en el ámbito de los derechos de la personalidad del menor tras las leyes del 2015¿Autonomía o intervención?", in: M.V. Mayor del Hoyo (dir.) *El nuevo régimen jurídico del menor: la reforma legislativa de 2015*, (Madrid: Dykinson, 2017), pp. 550-551. She considers that the intervention may consist in the accompanying, guide and advice of the parents, given that the legal representation is excluded.

to adolescents in decisions related to healthcare, and mainly those regarding abortion by adolescents over 16 and to the refusal of lifesaving treatment by adolescents. [12]

3 The child's autonomy in the context of healthcare

It is undeniable that the right to decide on one's own health constitutes a right relating to the personality. It is also clear, as stated above, that the minor's capacity evolves as he or she gets closer to adulthood. For this reason, the legal systems usually expressly provide that minors, despite their general incapacity, might gradually exercise their rights as patients. There are two basic criteria normally used to determine when a minor can exercise these rights: age and maturity. The former has the benefit of being an objective criterion, and therefore provides legal security for the professionals involved. However, its drawback is that age does not take the child's personal development, which might vary considerably between one child and another, into consideration. On the contrary, the criterion of maturity does consider the evolving personal abilities and faculties of every single child, but assessment of the capacity must be carried out on a case-by-case basis and for each specific intervention, which is arduous and creates insecurity for the doctor, who may be subject to possible legal proceedings.[13]

The Belgian Law of 22 August 2002 relating to patient's rights states that if the minor is able to reasonably appreciate his or her interests, he or she can exercise their rights as patients autonomously (Art. 12).[14] There is no age criterion for determining this aptitude, meaning that any child, regardless of his or her age, can be considered able to reasonably appreciate his or her interests.[15] It is also true that other specific acts in the Health Law field require a certain age for the recognition of the minor's capacity for specific interventions,[16] but the Law on patient's rights of 2002 is a *lex generalis*, applicable in the absence of specific laws,[17] and so is the criterion of maturity.

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[12] *Ibid*, p. 551. Also Andreu Martínez, *La autonomía del menor en la asistencia sanitaria y el acceso a su historia clínica* (Cizur Menor: Aranzadi, 2018), p. 41.

The Organic Law 2/2010 of 3 March, on sexual and reproductive healthcare and voluntary termination of pregnancy (Art. 13.4) allowed adolescents over 16 years to consent to terminate their pregnancy, informing one of their parents, except when this information could entail a serious risk for the women concerned. Organic Law 11/2015, of 21 September, abolished this Article and the current Article 9.5.II of the Law 41/2002 on patient's autonomy states that the termination of the pregnancy requires the express consent of the minor's legal representatives. For further analysis of these provisions, see Andreu Martínez, pp. 67-73.

[13] Aboaf, *supra* note 10, pp. 115-119.

[14] *Article 12*

§ 1er

Si le patient est mineur, les droits fixés par la présente loi sont exercés par les parents exerçant l'autorité sur le mineur ou par son tuteur.

§ 2

Suivant son âge et sa maturité, le patient est associé à l'exercice de ses droits. Les droits énumérés dans cette loi peuvent être exercés de manière autonome par le patient mineur qui peut être estimé apte à apprécier raisonnablement ses intérêts.

[15] G. Schamps, "The extent of minor autonomy and medical care in Belgian Law", in: B. Feuillet-Liger, I. Ryuichi, T. Callus (ed.) *Adolescents, Autonomy and medical treatment. Divergence and convergence across the globe*, (Bruxelles: Bruylant, 2012), pp. 86-87. G. Genicot, *Droit médical et biomédical* (Bruxelles: Larcier, 2016), p. 236.

[16] See A. Nottet, "Le mineur en droit medical", in*: Nouveaux dialogues en droit médical*, (Lien: Anthemis, 2012), p. 188 and onwards.

[17] Schamps, *supra* note 15, p. 85.

Under Spanish Law[18], before the rewording of Article 9.3.c) of Law 41/2002 of 14 November 2002, regulating patient autonomy and rights and obligations of information and clinical record, in 2015,[19] the scholars generally considered that this Law established a mixed criterion for determining the minor's capacity: it was necessary to evaluate the minor's intellectual and emotional ability to understand the extent of the medical intervention, but minors over 16 years old were presumed to have this capacity (Art. 9.3.c.II).[20] In this sense, it had been said that the medical adulthood had been established at 16 years old (notwithstanding other specific cases in which due to their importance, the law required the patient to be 18 years old). However, the wording of this Article 9.3, Paragraph c was criticised for being vague and incomplete,[21] and for using a negative formula to establish the autonomy of adolescents over 16.[22]

Article 9 of the Spanish Law 41/2002 on patient's autonomy was therefore reworded in 2015, and in the light of its new wording,[23] it is inevitable to ask if the legislator has also

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[18] In this study we will not mention the regulation of the different Autonomous Communities about children's autonomy in healthcare. As Andreu points out, the discrepancies between the State Law (after its amendment) and the Laws of the Autonomous Communities must be solved in favour of the first, at least in the case of those Autonomous Communities without jurisdiction over Civil Law. M.B. Andreu Martínez, *supra* note 12, p. 42.

[19] *Art. 9 (in force before Law 26/2015, of 28 July 2015)*
(…)
c) Cuando el paciente menor de edad no sea capaz intelectual ni emocionalmente de comprender el alcance de la intervención. En este caso, el consentimiento lo dará el representante legal del menor después de haber escuchado su opinión si tiene doce años cumplidos.
Cuando se trate de menores no incapaces ni incapacitados, pero emancipados o con dieciséis años cumplidos, no cabe prestar el consentimiento por representación. Sin embargo, en caso de actuación de grave riesgo, según el criterio del facultativo, los padres serán informados y su opinión será tenida en cuenta para la toma de la decisión correspondiente.

[20] See, among others: J. L. Beltrán Aguirre, "Los derechos de los menores de edad en el ámbito sanitario", in: A. Palomar Olmeda, J. Cantero Martínez (dirs), *Tratado de Derecho Sanitario*, Tomo I, (Cizur Menor: Thomson Reuters Aranzadi, 2013), p. 856; M.A. Parra Lucán, *supra* note 9, pp. 8-10; J. Cantero Martínez, "El consentimiento informado del paciente menor de edad: problemas derivados de un reconocimiento de su capacidad de obrar con distintas intensidades", *Derecho y Salud (*V. 18, nº 2), (2009), pp. 3-4.
However, this position was not unanimous. De Montalvo believes that the Law established an objective criterion, according to which minors over 16 years old were always able to decide, while the parents decided on behalf of those under 16. F. De Montalvo Jääskeläinen, "La autonomía de la voluntad del menor en el ámbito sanitario", in: M. Gascón Abellán, M.C. González Carrasco, J. Cantero Martínez (coords.), *Derecho sanitario y bioética. Cuestiones actuales*, (Valencia: Tirant lo Blanch, 2011), pp. 407-458.

[21] J. Cantero Martínez, *supra* note 20, p. 3; T. Hualde Manso, "Oposición a transfusiones e intervenciones médicas en situación de riesgo de los menores", *Revista Doctrinal Aranzadi Civil-Mercantil*, (n.º 10/2013), (2013), p. 3.

[22] Reproved by Beltrán Aguirre, *supra* note 20, p. 856.

[23] Article 9 (wording by Law 26/2015, of 28 July 2015 and Organic Law 11/2015, of 21 September 2015):
(…)
3. Se otorgará el consentimiento por representación en los siguientes supuestos:
(…)
c) Cuando el paciente menor de edad no sea capaz intelectual ni emocionalmente de comprender el alcance de la intervención. En este caso, el consentimiento lo dará el representante legal del menor, después de haber escuchado su opinión, conforme a lo dispuesto en el artículo 9 de la Ley Orgánica 1/1996, de 15 de enero, de Protección Jurídica del Menor.
4. Cuando se trate de menores emancipados o mayores de 16 años que no se encuentren en los supuestos b) y c) del apartado anterior, no cabe prestar el consentimiento por representación.
No obstante lo dispuesto en el párrafo anterior, cuando se trate de una actuación de grave riesgo para la vida o salud del menor, según el criterio del facultativo, el consentimiento lo prestará el representante legal del menor, una vez oída y tenida en cuenta la opinión del mismo.
(…)

introduced the subjective criterion of maturity for minors over 16 years old. Some authors believe so, considering the actual referral of Paragraph 4 of Article 9 (referring to children over 16 or emancipated) to Paragraph 3.c). In their opinion, the Law has stablished now a *iuris tantum* presumption of maturity for minors over 16, but the attending doctor can prove that an actual adolescent lacks the emotional or intellectual ability to understand the extent and consequences of the medical intervention.[24] Nevertheless, it is our belief that this interpretation is not consistent with the rules established elsewhere in the Article: the special mention of emancipated minors and minors over 16 would not be necessary if all minors, regardless of their age, are subject to the subjective criterion of maturity. In addition, the rule referring to situations of serious risk (Art. 9.4.II) constitutes an exception to the criterion according to which a minor over 16 years decides for himself. Accordingly, in our opinion the legislator did not mean to change the rule referring to the minors over 16, and the Law maintains that the age of majority is 16.[25]

The evaluation of the ability to reasonably appreciate one's interests (Art. 12 § 2 in the Belgian Law) or the intellectual and emotional ability to understand the extent of the medical intervention (Art. 9.3.c in the Spanish Law) thereby constitutes a crucial action in both legal systems.[26] The Belgian Law does not specifically state who must carry out this evaluation, but it is considered a task of the professional practitioner. [27] The Spanish Law specifies in Article 5.3 and 9.3.a) that the attending doctor is the person who must assess the ability of the patient, regardless whether the patient is an adult or a child. In any event, neither of the two Laws offers precise criteria to determine this ability, which will be quite difficult for the professional. The instruments or procedures that attempt to measure and objectify cognitive and volitional capacity do not seem useful for establishing the capacity of minors.[28] However, there is agreement that the assessment must take place on a case-by-case basis, and take into account not only age, but also other circumstances such as intelligence, maturity, personality, education, social situation, and the nature and the seriousness of the intervention proposed to the minor.[29] It also seems reasonable to demand a greater capacity when a consequence of the exercise of the right

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6. En los casos en los que el consentimiento haya de otorgarlo el representante legal o las personas vinculadas por razones familiares o de hecho en cualquiera de los supuestos descritos en los apartados 3 a 5, la decisión deberá adoptarse atendiendo siempre al mayor beneficio para la vida o salud del paciente. Aquellas decisiones que sean contrarias a dichos intereses deberán ponerse en conocimiento de la autoridad judicial, directamente o a través del Ministerio Fiscal, para que adopte la resolución correspondiente, salvo que, por razones de urgencia, no fuera posible recabar la autorización judicial, en cuyo caso los profesionales sanitarios adoptarán las medidas necesarias en salvaguarda de la vida o salud del paciente, amparados por las causas de justificación de cumplimiento de un deber y de estado de necesidad.

[24] See M. Jorqui Azofra, "Régimen jurídico de la autonomía de los menores de edad en el marco de las decisiones sanitarias", *Revista de la Facultad de Derecho de México*, (Tomo LXVIII, nº 272, 2018), pp. 480-483. D. Cadenas Osuna "El consentimiento informado y el rechazo a la intervención o tratamiento médico por el menor de edad tras la reforma de 2015: estudio comparado con el *common law", ADC,* (tomo LXXI, fasc. III, 2018), p. 813.

[25] According to Andreu Martínez, *supra* note 12, pp. 50-52. The scholar adds that the capacity of adolescents over 16 is largely accepted in practice, and used as a reference by other laws in the Health Law field. She also points out that the new wording of the article is inappropriate: point 4 should have referred to letter a) and b) of Paragraph 3 (respectively, the case in which the medical intervention is urgent, and the consent of the patient is not needed, and cases of patients with judicially restricted capacity).

[26] Particularly in the Belgian case, because the exercise of the rights depends entirely on this evaluation, while in the Spanish case the ability is affirmed for adolescents over 16 (apart from adolescents with their exercise modified judicially because of a disability (Art. 200, SCC).

[27] Schamps, *supra* note 15, p. 87.

[28] See R. Ojeda Rivero, "El rechazo al tratamiento médico por los menores de edad en grave riesgo", *Indret. Revista para el Análisis del Derecho*, (3), (2015), pp. 9-11, and the studies he cites.

[29] Nottet, *supra* note 16, pp. 158-159; G. Genicot, *supra* note 15, pp. 239-240.

of self-determination might be a serious impact on the minor's health, or even his or her death.[30]

In conclusion, in spite of further analysis in the next section, in Belgium the minor is able to exercise his or her rights as a patient whenever he or she is able to reasonably appreciate his or her interests. Otherwise, the parents will exercise these rights. In Spain, the minor will be able to exercise his or her rights if he or she has the intellectual and emotional ability to understand the extent of the medical intervention, and always if the minor is over 16 years old. However, as we will see, there is an important exception for interventions considered as risking the minor's health or life.

4 The refusal of treatment and the intervention of serious risk to the child's life or health

4.1 Minors able to decide for themselves

According to Article 12 of the Belgian Law of 22 August 2002 relating to patient's rights, if the minor is considered able to reasonably appreciate his or her interests, the Law allows him or her to exercise his or her rights as a patient autonomously, even if his or her parents disagree with the decision.[31] The child or adolescent is removed from parental authority, and his or her incapacity is revoked.[32] The Law does not impose any restrictions on the medical interventions about which the minor can decide, and therefore he or she may accept or refuse any treatment,[33] even if this refusal leads to the end of his or her life.[34] However, it must be recalled that the importance and vital nature of the medical act are circumstances that need to be seriously considered when evaluating the child's ability to reasonably understand his or her interests.[35] The physician must therefore be particularly attentive when assessing the child's aptitude and the interest of the planned intervention.[36] Apart from those provisos, after the child's aptitude has been established, he or she will be able to successfully object to his or her parent's preferences or choices, or accept treatments rejected by them.[37] The measure provided in Article 15 §2 of the Law of 22 August 2002, which allows the physician to act in the patient's interest and prevent every risk to his or her life or health, cannot apply here because it only permits to revoke the decision taken by the parents or guardians, and not those taken by the capable minor him or herself. The Belgian system is therefore coherent with the recognition of the child's ability to exercise his or her rights, despite the fact that assessment of this ability might not be an easy task.[38]

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[30] R. Ojeda Rivero, *supra* note 28, p. 11; M. Aboaf, *supra* note 10, p. 119; G. Genicot, *supra* note 15, p. 240. Taking note of the reasons that support doctor's assessment about the child's capacity seems advisable, too, according to Schamps, *supra* note 15, p. 87. A. Nottet, *supra* note 16, p. 159.

[31] Schamps, *supra* note 15, p. 90. Aboaf, *supra* note 10, p. 120.

[32] Nottet, *supra* note 16, p. 158.

[33] Genicot, *supra* note 15, p. 240.

[34] Nottet, *supra* note 16, p. 177.

[35] Aboaf, *supra* note 10, p. 119.

[36] Schamps, *supra* note 15, p. 90.

[37] Aboaf, *supra* note 10, p. 119. For instance, the use of contraceptive measures.

[38] Though this issue is beyond the scope of this paper, we would at least like to mention that according to the Belgian Law of 28 May 2002, related to euthanasia (wording of the Law of 7 February 2014) a minor can request euthanasia and the medical practitioner does not commit an infraction when: the minor is capable of discernment; the demand is made voluntarily, reflected and repeatedly, free of external pressure; the child is in a medical situation of constant and unbearable physical suffering that cannot be relieved, and which will lead to death in a short period of time due to a grave and incurable affection (art. 3 §1). The

On the other hand, the Spanish system has always been more suspicious about the possibility that the minor, despite being considered mature, could make a decision with irreversible consequences for his or her life or health, especially when he or she refuses the recommended treatment considered necessary by the doctors.

The former wording of the second Paragraph of Article 9.3.c of the Spanish Law 41/2002, on the patient's autonomy[39], after stating that representation was not possible if the patient was over 16 years old (and therefore consider him or her able to consent by him or herself), added a specific rule for cases "*of serious risk, according to the physician's criterion":* the parents had to be informed and their opinion be taken into account when the corresponding decision was made. But what was the role of the parents in these cases of serious risk?

Some scholars believed that above all, parental authority was completely ruled out according to the Article, and that the decision corresponded to the minor, as a person fully capable of exercising his or her rights.[40] This meant that the parents must be just listened to. A different interpretation, which is widespread among the scholars, is that according to the wording of the Article, parental authority was excluded, and as such the legislator did not aim to attribute the decision to the parents. Nor could the Article be addressed to the minor, because it would be absurd to proclaim his or her autonomy and compel him or her to take the opinion of his or her parents into account. As such, everything seemed in their opinion to indicate that the decision was in the hands of the doctor ("…*according to the physician's criterion*, …").[41] There were also other interpretations, which held that the decision rested with the parents, based on the protection of the child's right to life[42], or that the child's consent should agree with the parent's consent.[43]

These different interpretations constitute one factor that explain the rewording of the Article 9 in 2015. However, the 154/2002 Constitutional Court's sentence of 18 July 2002,[44] and Instruction 1/2012 of 3 October 2012, by the Attorney General, on the

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child's capacity for discernment is therefore the key factor in the child's euthanasia, which has been found to be completely coherent with the Law on patient's rights (Aboaf, *supra* note 10, p. 122-124), although the parents must receive the same medical information as the child, and must agree with the patient's request (art. 3 §2).

[39] See footnote 19.

[40] A. Domínguez Luelmo, *Derecho sanitario y responsabilidad médica* (Valladolid, Lex Nova, 2007).

[41] Parra Lucán, *supra* note 9, p. 8 understood that this interpretation was inadmissible and incoherent with the ruling about informed consent. Having excluded representation when the minor is capable, it would be surprising if the decision were attributed to medical practitioners in cases of serious risk.

[42] F. De Montalvo Jääskeläinen, *supra* note 20, pp. 428-429, A. De Lama Aymá, *La protección de los derechos de la personalidad el menor de edad* (Valencia: Tirant lo Blanch, 2006), pp. 320-322.

[43] Parra Lucán *supra* note 9, p. 7, understanding that the parents act according to their duty to protect their children (Art. 154 SCC), which is enforceable despite of the lack of legal representation.

[44] This case was about a 13-year-old child Jehovah's witness, whose parents refused him to undergo a blood transfusion after an accident. Given the parent's refusal, the compulsory transfusion was authorised by a court, but when the physicians tried to carry it out, they encountered strong and forceful physical opposition from the child, and they decided that the compulsory treatment was counter-productive. The boy finally died, and his parents were charged and convicted with manslaughter by the Supreme Court, on the understanding that their duty was to preserve their son's life, and that they should have done more to convince their son to accept the transfusion. The Constitutional Court decided that there were not enough circumstances in the case to consider the minor capable of exercising his right to refuse the treatment, and as such the decision rested with the parents, and not with him. In this context, the best interest of the child, as maintained by the parents or by the Courts, always prevails, and life is a higher value in the constitutional legal system and a requirement for the remaining rights to be possible. Accordingly, as their son's legal representatives, the parents were in a position of guarantors of their son's life. However, even in this position their own constitutional rights must be respected. They did try to provide their son with proper medical care, and attempted to seek an alternative to blood transfusion, and they certainly did not oppose the blood transfusion authorized by the Court (an authorization which in the Constitutional Court's opinion

substantive and procedural treatment of conflicts over blood transfusions and other medical interventions on minors in cases of serious risk[45], also had a clear influence on that redrafting.

So in 2015, the wording of the second Paragraph of Article 9.3.c) was changed, and the current second Paragraph of Article 9.4[46] states that in the event of an action entailing serious risk for the life or health of the minor according to the physician's opinion, consent must be given by the minor's legal representative once he or she has been heard, and his or her opinion been taken into account. It is now clear that the parents will make the decision, meaning that the controversy about who decides appears to be over.[47] But according to the new Paragraph 6, the parents or representatives must always decide while considering the most beneficial course of action for the patient's life or health. Otherwise, the doctors can ask the Court for an authorization to that end, unless it is an urgent intervention, when the medical practitioners may act to safeguard the patients' life or health, on the grounds of fulfilment of their duty and a situation of necessity.

This redrafting has clearly adopted the criteria provided by the General Attorney's Instruction of 2012, previously upheld by some scholars,[48] placing the protection of the life and the health of the minor above his or her autonomy, because the latter is considered a preferential value of our legal system.[49] Furthermore, the Law now establishes a clear criterion that has been said to provide legal certainty, which was much demanded by professionals.[50] With the current wording of Articles 9.4 and 9.6 Law 41/2002, on patient's autonomy, in the event of a medical intervention with serious risk for the minor's life or health, even if he or she is over 16 or under 16 but mature, it is clear who exercises

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was constitutionally granted to save the child's life), but no further action contrary to their religious beliefs (Art. 16 Spanish Constitution) could be demanded of them.

Although there was no proof of the child's maturity, the Constitutional Court also stressed that he showed strong convictions and consciousness of his decision, and this could not be ignored either by his parents or by the Court that authorised the blood transfusion. This means the child's opinion should have been considered. In Beltran's opinion, it also means that if there had been proof of the child's maturity, the Constitutional Court would have ruled in favour of this right to refuse the treatment. Beltrán Aguirre, *supra* note 20, p. 867.

[45] Available in https://www.fiscal.es/fiscal/PA_WebApp_SGNTJ_NFIS/descarga/CIRCULAR%201-2012.pdf?idFile=7b9a2a61-9fd8-4422-9f76-cabecec2961e

This document was dictated with the purpose of guiding Attorneys' actions, especially in cases where blood transfusions are refused on religious grounds, but extends to any other case in which the refusal of an intervention may entail a serious risk to the life of the child because of the irreversible effects of the medical intervention. In these cases, according to this Instruction, the conflict between the life or health of the underage patient and his or her autonomy, exercised directly by the minor (when emancipated, over 16 or considered mature) or indirectly through his or her legal representatives, must be resolved by giving priority to the child's best interest, which is identified as the protection of his or her life and health.

[46] Confront footnotes 19 and 23.

[47] Although the first sentence of Article 9.4 excludes representation. It could be said that a child may now exercise his or her right to consent only in the case of minor interventions (vaccinations, dental treatment, primary care, etc.).

[48] See footnote 42. In the same direction. N. De la Horra Vergara, "La incidencia de la Ley 26/2015 en la Ley 41/2002 sobre capacidad de los menores de edad en el ámbito sanitario". *Adolescere* 2016. Vol IV. Nº 1, 2016, p. 40. On the contrary, Lomas believes that the current wording is contradictory to the aforementioned ruling, which stated that the minor was exercising his right of self-determination over his body. V. Lomas Hernández, *"Minoría de edad y derecho sanitario: la Ley Orgánica 8/2015, de 22 de julio, y la Ley 26/2015, de 28 de julio"*, Juristas de la Salud, 2015, available at: http://www.ajs.es/blog/minoria-de-edad-y-derecho-sanitario-la-ley-organica-82015-de-22-de-julio-y-la-ley-262015-de-28-de-julio.

[49] As allegedly stated by the Constitutional Court's Sentence 154/2002. See note 44.

[50] Nevertheless, it is necessary to determine when a specific medical intervention might entail a serious risk to the minor's life or health, as pointed out by Andreu Martínez, *supra* note 12, p. 52.

the right to consent: the parents. And the criterion they must follow in their decision is also clear: the most beneficial intervention for their child's life or health.

This new wording has been welcomed by some scholars, because in addition to ensuring the protection of the child's life, clarifying the wording of the Law and providing legal certainty, along with the other 2015 reforms regarding children's autonomy, it aims to facilitate the exercise of parental responsibility, because before these legal changes, parents were said to be still obliged to take care of their children, but lacking the most basic resources for the effective protection of the child, whenever he or she was considered mature enough to decide for him or herself.[51]

Nevertheless, not all opinions on this legal modification are positive. Other scholars believe this rewording clearly restricts the autonomy of the minor, only after declaring him or her able to decide and exercise the right to consent by himself or herself (Art. 9.3.c and 9.4 Law 41/2002 on patient's autonomy).[52]

We consider that the role of the parents, in this specific field of healthcare decisions, has not been reinforced or restored in order for them to fulfil their duty to take care of their children, as stated above. This would be the case if they could decide which medical option is, in their opinion, the best one according to their child's best interests, even if this is contrary to the child`s own opinion. But they cannot really make this judgement, because if their decision is against the doctor's opinion, the practitioner may notify a Court and apply for a judicial authorization that allows the intervention to take place. This alleged increased reinforcement of the parent's position is, therefore, only formal.[53]

The key point is now that the Law identifies the best interest of the child with the preservation of his or her life or health, as stressed by ANDREU.[54] This identification may be valid in the cases where a blood transfusion is refused (by the child or by the parents) on religious grounds, and avoidance of these refusals lay at the origin of the General Attorney's Instruction 1/2012.[55] Nevertheless, whether this identification could be extended to all the cases involving crucial interventions should be seriously questioned.

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[51] García Alguacil, *supra* note 11, pp. 548-549. Unfortunately, we cannot address here the extent and importance of these legal changes, which are beyond the scope of this paper, and we limit our analysis to this issue in Law 41/2002 on patient's autonomy.

[52] Andreu Martínez, *supra* note 12, p. 55. N. De la Horra Vergara, *supra* note 48, p. 41. V. Lomas Hernández, *supra* note 48.

If the purpose of the changes on Article 9 of 2002 Law on patient's autonomy was to avoid "wrongful" decisions by minors or adolescents who are capable according to that Law, or establishing some sort of parental control over them, highlighting the vulnerability of the child in this context, other less radical measures than overruling the child's autonomy could have been provided, such as requiring a joint decision by the parents and their son or daughter, or demanding an assessment of the ability of minors over 16 years old.

[53] In fact, the Instructions of the Attorney General stated that in the event of the parents refusing a treatment, if the child accepted it, his or her "autonomy" prevailed over the parent's refusal.

[54] Andreu Martínez, *supra* note 12, p.55-56.

[55] The Constitutional Court's Sentence 154/2002, of 18 July 2002, ruled that the preservation of the child's life could not be overruled by the parents' freedom of religion. Furthermore, Ojeda points out that when a child or adolescent refuses a blood transfusion on the grounds of his or her religious beliefs, this is not really consent, because the child is by definition vulnerable and under the influence of a religious group, and therefore he or she does not assume the religious doctrine motivating the refusal with full freedom and conscience. R. Ojeda Rivero, *supra* note 28, pp. 26-27.

In Belgium, the Avis nº 16 du 25 Mars 2002 relatif au refus de transfusion sanguine par les Temóins de Jéhovah, from the Comité Consultatif de Bioethique also addressed this issue. If the minor is not capable, the Committee considers that according to International treaties (Art. 2 of the European Convention of Human Rights, Art. 8 of the Convention on Children's rights) the child's right to life must be guaranteed and no exception can be made based on the parents or legal representatives' rights. As a result, with some provisos (establishing a dialogue with the parents, if possible, and asking three different doctors to ascertain

The UN Convention on Rights of the Child of 20 November 1989, recognises that every child has the inherent right to life, and the States parties' obligation to ensure the survival, growth and development of the child (art. 6), including the physical, mental, moral, spiritual and social dimensions of their development, which constitutes an essential factor in determining the child's best interest.[56] However, at the same time, other criteria need to be considered to determine this best interest, and in particular the right of the children to express their views on every decision that affects them (Art. 12).[57] Article 2.2 of the Spanish Organic Law 1/1996 on the legal protection of children and adolescents states that the children's best interest must be determined case by case, and provides a non-exhaustive and non-hierarchical list of elements that could be included in a best-interests assessment to determine a child's best interests.[58] Accordingly, it seems that the best interest of the child cannot be identified with a single and predetermined element,[59] established by the legislator for a certain act, just as in Law 41/2002 on patient's autonomy in interventions of serious risk.

It would not be hard to find a case in which an adolescent with a chronic disease is able to understand his or her illness and the extent and consequences of the medical cares, and able to receive the medical information and to consent medical treatments, being, therefore the protagonist of his or her own medical process. However, according to current Article 9.4 of the Law on patient's autonomy, as soon as an intervention involving a serious risk arises, he or she will be deprived of this autonomy, and the law will instead replace not only his or her autonomy, but also his or her parents' faculties.[60] We could consider a case like Hannah Jones'[61] and wonder what the approach to a case like this

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the vital nature of the blood transfusion) the physician can perform the transfusion (pp. 21-23). When the child or adolescent is considered capable and refuses a blood transfusion, the Committee states that doctors must take into careful consideration the age and maturity of the child and the relevance and consequences of the failure to perform the transfusion, be sure that the patient fully comprehends the medical intervention and its consequences, and ensure there is no influence from the parents or the religious congregation. Given these circumstances, the child's refusal of the blood transfusion must be respected.

[56] According to General Comment nº 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (Art. 3, para. 1), p. 16, and General Comment nº 12 (2009), on the right of the child to be heard.

[57] When it comes to healthcare decisions, the General Comment nº 14 states that (p. 16): "*if there is more than one possible treatment for a health condition or if the outcome of a treatment is uncertain, the advantages of all possible treatments must be weighed against all possible risks and side effects, and the views of the child must also be given due weight based on his or her age and maturity".* It is also recognised the right to be included in decision-making processes, in a manner consistent with their evolving capacities, and be allowed when possible to give their consent in an informed manner (p. 23).

[58] These are: a) the protection of life and development of the child; b) respect for his or her wishes, feelings and opinion and involvement in the decision-making processes, according to the age, maturity and personal development; c) preservation of an adequate family environment free of violence; d) preservation of the child's identity.

[59] See Andreu Martínez, *supra* note 12, pp. 32-35. C. Guilarte Martín-Calero, "La configuración del interés del menor ex artículo 2 de LOPJM y su posible aplicación a la determinación del interés de la persona con discapacidad intelectual o mental una propuesta", in: M.V. Mayor del Hoyo (dir.) *El nuevo régimen jurídico del menor: la reforma legislativa de 2015*, (Madrid: Dykinson, 2017), pp. 497-503. She believes, though, that the protection of life is a prevalent factor in all of them.

[60] This will only happen if the child's decision (or the parents' decision if he or she is not mature) is contrary to medical opinion, mainly when a treatment is refused with probable irreversible consequences for the child's health or life. Spanish Law is therefore now considering all decisions that do not benefit life or health itself as wrongful decisions.

[61] Hannah Jones was a British girl who was found to have leukaemia at the age of four, and refused the heart transplant that could save her life at the age of 13. She decided that could not stand the suffering of

would be according to the current Spanish Law. The physician could assess the child's or adolescent's competence to consent to the medical treatment, and could understand or agree with his or her motives to refuse it, but then a dilemma arises for the doctor: if Article 9.4 strictly applies, the physician would be obliged to perform the intervention as it is considered the most beneficial act for preserving the adolescent's life or health, albeit against the patient's will;[62] if the physician respects the capable minor's refusal of the treatment, he or she could be held responsible for breaking the law and not asking for the Court's authorization or failing to act in case of an emergency. So, though at first sight the rewording of Article 9.4 could be considered to offer legal certainty for medical practitioners, in our opinion it might create specific new problems.

4.2 Minors unable to decide for themselves

If the child is not able to exercise the right to consent on his or her own[63], the parents (or legal representative) must exercise the right to consent[64] as an expression of their parental authority. The child's opinion must be heard before making that decision.[65] Our interest focuses again on those situations in which the parents refuse a lifesaving intervention, or make a decision that might have irreversible consequences on their son's or daughter's life.

In the Belgian Law, the parent's decision, as made in the exercise of their parental authority, must respect the child's best interest.[66] If the parents are not defending this best interest, demanding a futile or an extremely risky medical intervention, or refusing a necessary treatment, Article 15 of the Law relating to patient's rights allows the physician "*in the patient's interest and to prevent every threaten to his or her life or every act with serious consequences over his or her health*" to deny the parents access to the child's clinical record, and even the exercise of informed consent.[67] The physician therefore safeguards the child's best interest as an alternative to the parents.[68]

In the Spanish case, parental authority also must be exercised in the child's best interest, but Paragraph 6 of Article 9 Law 41/2002 on patient's autonomy states in its current wording that the parent's decision must always be adopted according to the most benefit to the life or health of the patient. The conflict arises if the parents, following their child's

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more medical interventions and decided to go home. She was found to be competent, able to determine her own best interest, and therefore her decision was respected, although it meant that she was going to die.

[62] To avoid this, the medical practitioner would have to argue that the intervention is not the most beneficial option, due to its high risk or uncertain outcomes.

Article 9.4 Act 41/2002 would not apply when the child suffers a terminal illness that is going to cause his or her death anyway and refuses a treatment, as suggested by Jorqui Azofra, *supra* note 24, p. 495. In that case, there is no serious risk to the life or health of the child.

[63] According to the Belgian Law, this is a child who is unable to reasonably appreciate his or her interests (Art. 12 Belgian Law 22 August 2002 relating to patient's rights); according to the Spanish Law, it is a child under 16 years old who is unable to intellectually and emotionally understand the extent of the medical intervention (Article 9.3.c of Law 41/2002 on the patient's autonomy). The only difference therefore refers to adolescents over 16, who are considered competent in the Spanish case, while in Belgium their ability must be assessed by the physician.

[64] However, this does not exclude the minor's right to receive information: the minor will receive partial and simplified information, in an understandable language according to his or her age or maturity. Article 5.3 of the Spanish Law 41/2002. See Nottet, *supra* note 16, p. 165.

[65] According to Article 9.3.c) of the Law 41/2002 on patient's autonomy.

[66] Nottet, *supra* note 16, pp. 153, 155-156.

[67] It would be necessary to call an interdisciplinary meeting to overrule the parents (Art. 15 § 2), and to note it down in the medical record (Art. 15 §3).

[68] Nottet, *supra* note 16, pp. 160-161. Genicot, *supra* note 15, adds that apart from undergoing the medical act, if the parents refuse a necessary and non-urgent intervention for the child, the physician can ask a Family Court to authorise the medical procedure in the child's best interest (Art. 387.bis BCC).

opinion or otherwise, decide against that major benefit, and particularly when they refuse a treatment.[69] The aforementioned criticism regarding the identification of the child's best interest with the preservation of his or her life or health is fully applicable here.[70]

Whenever the parents do not adopt the most beneficial decision for their child's life or health, the current Article 9.6 expressly entitles the doctor to notify an Attorney or a Court directly, and ask for a judicial decision.[71] In any case, if the medical intervention is urgent and there is no time to ask for judicial authorization, the physician can perform the interventions required to safeguard the life or health of the patient, under the justification of fulfilment of duty and a state of necessity. Article 158 of the Spanish Civil Code already allowed a Court to take any measure to avoid a situation of danger for the child, or to avoid any harm to him or her, so we believe that the rewording of Article 9.6 is really addressed at medical practitioners, in the sense of offering them certainty that they will not have to face a malpractice lawsuit if they overrule the parents or the child's decision.

5 Conclusion

It is a fact that children gradually acquire more abilities as they grow up and mature, and legal systems tend to admit the legal validity of certain acts performed by the child autonomously, despite his or her general incapacity. Within those acts, the provision of consent for medical interventions is a particularly sensitive one: the decision of a child or adolescent adopted without full capacity, without full awareness of its consequences, could have terrible and irreversible repercussions on his or her life or future well-being. It is therefore natural that precautions should be taken to avoid such negative effects.

Belgium's 2002 Law on patient's rights attributes to the minor the exercise of his or her right to consent, provided that he or she is reasonably able to appreciate his or her interests, without any restriction on the type of acts he or she can consent to.[72] The determination of the minor's autonomy is therefore based entirely on the assessment of his or her capacity, a task that has been described as difficult and sometimes uncertain. However, the importance of the medical intervention and the significance of its consequences must be taken into account in a careful assessment of the child's ability.

The Spanish 2002 Law on patient's autonomy initially follows this pattern, and supports the exercise of the right to consent if the child is intellectually and emotionally able to understand the medical procedure and its consequences, and even considers that adolescents over 16 years old always are capable. Nevertheless, at the same time it currently stipulates that regardless of the child's competency, when there is a serious risk for his or her health or life according to the physician's opinion, the parents must exercise

[69] It must be stressed out that this Paragraph does not require a situation of serious risk for the minor's life or health (as opposed to Article 9.4, which is applicable to children able to exercise their rights on their own), and as such it could be cited in other cases.

[70] It could be pointed out that in some cases of representative decisions, a contradiction may arise between the rule in Article 9.6 and the one in Article 9.7, which states that those decisions must be "*appropriate to the circumstances, proportionate to the needs that must be provided, in favour of the patient and with respect to his or her personal dignity*". Nevertheless, Article 9.6 was reworded in 2015, and is a subsequent law, and the legislator's intention was to avoid the child or his or her parents or legal representatives making decisions with irreversible consequences on the life of health of the child, meaning that Paragraph 6 would apply whenever their decision does not involve that major benefit.

[71] Paragraph 6 only states that the Court will adopt the "corresponding" decision. To be consistent with the Article, it must be authorisation of the medical act with the most benefit for the child's life or health.

[72] Though, as previously mentioned, other Laws could require certain age for certain medical acts.

the right to give informed consent, after listening to the child's opinion (Art. 9.4.II), and , the parents must make the decision that is most beneficial to his or her life or health (Art. 9.6). The identification of the child's best interest with a single factor, the preservation of the child's life, has been already criticized. But going beyond the specific cases of Spain and Belgium, we can conclude that the conflict between autonomy and protection really arises when the child must face healthcare decisions that pose a risk for his or her life or health, outstandingly the refusal of a treatment. In these cases, a higher capacity can be demanded in the child, according to the importance and consequences of the decision. But some legal systems also might break in these cases the apparent consensus in the recognition of the children's autonomy, derived from their fundamentals rights' recognition, to protect and safeguard their future life above their autonomy, in the name of the fundamental right to life.