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Special article

Recommendations for attending patients who refuse hemoderivatives therapy[☆]

Recomendaciones para la asistencia a los pacientes que rechazan el tratamiento con hemoderivados

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ARTICLE INFO

Article history:

Received 3 November 2016

Accepted 17 December 2016

Available online xxx

Introduction

In contemporary medicine the principle of autonomy is the guiding principle of the relationship between doctor and patient. Consequently, people have the right to choose between those treatments offered by the health system, the most suited to their beliefs, values and interests. The doctor's duty is to inform the patient about the treatments available and, with few exceptions, to refrain from acting if the patient does not give his/her consent. Besides, the professional may incur criminal liability if the patient is treated without consent.^{1,2}

Moreover, the doctor continues to occupy a guarantor position regarding the interests of incapacitated persons and minors entrusted to their care. Consequently, the doctor has no obligation to comply unconditionally with the will of the representatives when, in his/her view, they act contrary to the interests of the patient.

As regards the possible conscientious objection of the professional, although this is a controversial issue, we understand that letting a person who refuses treatment die on religious grounds may be an unacceptable moral conflict for some professionals, therefore, health centres should have procedures governing this

issue.³⁻⁷ Of course, those procedures must, in turn, guarantee the patient's right to health care when they refuse treatment with blood products.

Ethical and deontological considerations

When a person endangers his/her life because of refusing a medical treatment, respecting their will seems contrary to the physician's duty regarding ensuring the patient's welfare. However, this conflict is only apparent and is due to a confusion between the technical and ethical dimensions of medical duty:

"The imposition of a treatment, even if indicated from a medical point of view, causes the person a moral damage that, today, we consider unacceptable. A transfusion to save the life of a person is, technically, a correct action, but to do so without the patient's consent is ethically and deontologically wrong".

Moreover, personal beliefs cannot be the basis for demanding treatments which are different from those available to the general population. Providing a healthcare system user, a certain type of assistance based on his/her beliefs might be discriminatory with respect to the rest of the population: Such a situation would happen in the case of Jehovah's Witnesses if, for example, treatments alternative to the transfusion of blood products, associated with fewer risks, were to be applied to them preferably.

In practice, we must find a reasonable balance between the patient's right to choose freely the treatment you want and the duty of public services to treat all citizens equally.

[☆] Please cite this article as: Ojeda Rivero R, Jiménez López I. Recomendaciones para la asistencia a los pacientes que rechazan el tratamiento con hemoderivados. Med Clin (Barc). 2017. <http://dx.doi.org/10.1016/j.medcli.2016.12.010>

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The legal framework

The patient's right to refuse treatment

The right of people to choose from the available clinical options and refuse medical treatment has been expressly recognized in Articles 2.3 and 2.4 of Law 41/2002 of 14th November, regulating patient autonomy and rights and obligations regarding clinical information and documentation (hereinafter PAL). The doctor can only treat the patient without his/her consent when there is a risk to public health (art. 9.2.a) or a serious immediate risk to the physical or mental integrity of the patient and obtaining the patient's authorization is an impossibility (art. 9.2.b). In any other circumstances, treatment refusal of the elderly patient who is able to decide by himself/herself must be respected, even when his/her life is at risk, as recognized by various regional laws governing the individual's rights and guarantees in the process of death.⁸

This right has also been recognized by the Constitutional Court (CC) in numerous sentences,⁹⁻¹³ arguing that the patient's right to choose his/her treatment is "the most important manifestation of the fundamental rights that may be affected by medical intervention", which must be respected "even if it could lead to a fatal outcome".

In short, both from an ethical as well as a legal point of view, when an elderly and capable person, explicitly and freely rejects the proposed medical treatment, the doctor's duty is to respect the will of the patient even if it means letting them die.

The right to receive specific health care

Although patients have an almost absolute right to refuse treatment, they have no equivalent right regarding receiving specific treatment due to being the best suited to their values or beliefs. The doctor has no obligation to perform a treatment simply because the patient requests that treatment. Treatments contrary to the *lex artis* (standards of professional excellence) or treatments that are not indicated for the patient's disease are to be avoided.

The health system should not meet the demands that are contrary to the principle of justice. This restriction, whose ethical foundation was discussed earlier, has been endorsed by both the Supreme Court and by the CC, who have confirmed that personal beliefs may not result in favoured treatment by the Administration.¹⁴⁻¹⁷ In the words of CC, "art. 14 of the Constitution recognizes the right to freedom from discrimination, but not the hypothetical right to impose or demand differences in treatment".¹⁸

However, usually, Jehovah's Witnesses do not ask for "a type of medical care to which they are not entitled, but only that the medical care is provided in conditions that do not violate their religious beliefs".¹⁹ In such cases, if the technical restrictions that the patient requests are acceptable from a medical point of view and treatment is the same as the one provided to the rest of the population, denying patient care would be discriminatory.

Therefore, in general, the doctor has a duty to assist Jehovah's Witness patients with absolute respect for the restrictions derived from their beliefs. However, the doctor would not be compelled to give the patient the specific treatment he/she requests when: a) the refusal of blood products means the treatment is no longer indicated from a medical point of view, or b) when providing the assistance that the patient requires amounts to a special or preferential treatment.

Informed consent

Characteristics of the informed consent

Certain aspects of the informed consent are particularly relevant in this group of patients.²⁰ First of all, treatment refusal should be done voluntarily and freely. The patient should not be manipulated or pressured and should have the opportunity to express his/her will in private. In addition, the patient should have enough information to decide. The doctor has a duty to provide such information in a clear, accurate and understandable way. The refusal of treatment should always be in writing. The doctor must enter all relevant details of the patient's information and decision procedure in the medical record.

Consent or refusal of treatment can only be given by people with ability to decide for themselves. This capacity is presumed when the person reaches legal adult age, time when a *legal capacity to act* is acquired. Only a court order can break this presumption.²¹ In such a case, the person is *legally incapacitated* and may only take the decisions specified in the sentence, which may be limited to declaring a partial disability. Any decision that the incapacitated person cannot make by himself/herself will correspond to his/her legal representative.

Moreover, elderly patients may be unable to decide "*in reality*", even when not legally incapacitated. In a healthcare setting, it is the physician who determines this issue.²² If the doctor considers the patient unable to decide, he/she will inform those related to the patient by family or "de facto" ties, and will ask their consent to treatment. Also, in the case of minors, consent to treatment generally corresponds to their parents or legal guardians, although in some situations, the child can decide for himself/herself, as we shall soon see.

Treatment refusal by representation

An incapacitated patient's consent to treatment is to be granted by persons related to him by family or "de facto" ties, or by his/her legal representative. According to the CC, the representative must always act "in the interest of the incapacitated".²³ In the same vein, the Civil Code states that parents are required to exercise parental authority "always for the benefit of their children"²⁴ and the PAL requires the representative to act "with due regard to the greatest benefit to the life or health of the patient" (art. 9.6). All this, of course, independently from the fact that the patient needs to be informed and involved in decision-making to the extent permitted by his/her condition.

When doctors consider that the decision of relatives or representatives is contrary to the interests of the incapacitated patient, they may resort to the advisory opinion of a Healthcare Ethics Committee. If the disagreement persists, it should be made known to the judicial authority. Doctors are guarantors of the interests of the incapacitated person who is entrusted to their care and have no obligation to abide by the decisions of the representatives if they consider them harmful to the patient, although, in these cases, they should seek judicial authorization for treatment.

Advance directives or living will declaration

The right to issue an advance directive (AD) is found in Article 11 of the PAL and allows the person to express his/her will on those treatments the person wants or does not want to receive in the future, if incapacitated. For practical purposes, the value of an AD is equivalent to a treatment consent or refusal directly expressed by a fully capable person. If the patient has rejected certain

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