

## Short Note

# Palliative Care: A Challenge

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Given the progress acquired by medical technology, the Spanish legislature has begun to address regulation on some of the aspects that relate to the justification of euthanasia and medical assisted suicide. However, in the same period of time very little attention has been paid to the development and proper use of palliative care and pain mitigation in the terminally ill patient. This is no doubt a delicate issue, especially considering that the use of these techniques require the participation of third parties unknown to the patient and in most cases involve the intervention of a medical professional. This has generated an important discussion forum that has given voice to a diversity of professionals from various health-related fields such as: lawyers, ethicists, politicians, and the general public. Legislative changes [1] did not lag behind and both in the autonomous community of Andalusia (where there is already a Law in place as well as in other communities such as Aragon, Navarra, the Canary Islands, Balearic Islands and Galicia [2]) and at the state level many activities and initiatives materialized in this regard. The only bill drafted during the Zapatero government stated that terminally ill people will be guaranteed the right to have their wishes regarding the treatment they would receive at the end of their life. Furthermore the drafted law proposal guaranteed the right to accurate information on the state of health of the patient. According to the bill mentioned above, "terminal situation" is understood as an instance where the patient has an advanced, incurable, or progressive disease where there is no reasonable chance of response to specific treatment. In addition, with a life expectancy of weeks or months in which the symptoms may require specialized palliative care. Also noteworthy in this bill was the initiative to recognize, as patient rights; palliative care, including sedation to alleviate pain; the right to privacy for the patient and its family; the right to spiritual counseling to the extent of their beliefs; and the right to a private room at the hospital during the final phase leading to death.

Finally, to briefly describe the Spanish regulatory context it

1 In April 1997, a Convention for the Protection of the Rights and Dignity of the Human Being, in which reference was made to biological and medical applications in this sector, was held in Oviedo [1]. In it the foundation of what later would be the basis for legislation throughout the national territory and, more particularly, in the different autonomous communities were established. Vid.

2 In Andalusia, we should note the Ley 2/2010, of 8 April, "De derechos y garantías de la dignidad de las personas en el proceso de muerte" (BOJA nº 88, de 7 de May) [1]. In Navarra the Ley Foral 8/2011, de 24 de March, "De derechos y garantías de la dignidad de la persona en el proceso de la muerte" (BON de 4 de April). In Aragón, the Ley 10/2011, de 24 de March, "De derechos y garantías de la dignidad de la persona en el proceso de morir y de la muerte" (BOA 7 de April).

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is necessary to refer to, as previously mentioned, the prevailing Law 41/2002 "básicareguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica", where some relevant concepts are defined in this area such as: "responsible physician", right to care information", "informed consent", and advanced directives".

Currently there is a trend to consider eliminating sanctions for doctors who are willing to hasten the process of death in their terminally ill patients. This is coupled to the establishment of a system that supposedly allows patients to decide how to spend their terminally ill phase. However, these two possibilities pose serious problems. In the latter, such decisions are often taken by people who are vulnerable, sometimes due to their advanced age, the pain caused by the disease, or because they are suffering from social isolation. Since we are describing situations where physical pain and social abandonment is significant the freedom of choice a person has in these cases is affected. Therefore the means to guarantee a "free decision" in such an important issue such as the right to live or die can only be achieved when the patient is offered effective palliative care, which can eradicate the pain and suffering caused by the disease, although not the disease itself. Only this way the patient has the opportunity to spend the terminal phase of the disease in peace and free of pain, one can decide "freely". Otherwise there is no "freedom of choice". It can be argued that induced death is a less expensive, more decisive, and more effective method against pain, in as much as by ending life you stop the pain and suffering. However, it cannot be argued that it leads to a dignified life, since the only benefit is ending pain and suffering. Therefore these solutions favor death.

There are at least two sensitive issues raised by these arguments. The first one relates to the possibility that terminally ill patients feel coerced into dying due to the lack of choices if not offered palliative care. In the absence of pain fighting treatment patients could act on desperation and against their own wishes. The other issue to consider is lost of control over one of the most important decisions in life, which is to end it.

It seems imperative that before taking any legislative action, there needs to be a careful study and debate to act with sufficient caution regarding the establishment of measures to be taken against the lives and freedoms that affect groups of people suffering pain and therefore will be subject to these.

The fact that our society has begun to sue health care professionals (doctors) who are acting, in certain cases, as “agents of death” (“executioners”) has generated several controversial discussions questioning this assumption “duty”. In such discussions, frequently moral principles contradict the ethical duties, raising questions about safety. Ideas about the autonomy of people who are terminally ill are configured within the alleged framework of their “right to free disposal of life”. One issue that seems very relevant, in this debate, is precisely the reference value that, in these cases, you have to give to the moral conscience of medical professionals [3]. Since these professionals are not indifferent to some of the questionable processes that are under discussion in the debate about the rapeutic death or are not robots that are exempt from moral judgment; surely, they will be affected in some important aspects of their work or their social contribution, even creating a situation where they are acting against their Hippocratic oath.

Moreover, we should also expect that any legislative change or reform could generate possible contradictions (antinomies) in the legal system in which they are implemented (especially in civil law systems). Generally antinomies derived from criminal codes or standards that still conceived human life (in its main forms of manifestation) as a “good” legally protected. What these standards precisely try to defend indiscriminately is life from any type of attack that it can receive [4]. We must therefore be aware that the way in which these articles are written, which deal with protecting life, are significant to the true protection granted to it [5].

In general, if we in our legal positioning in this issue allow ourselves to be seduced by the principle of autonomy of people, it will seem as if the broad debate is summarized only in the simple possibility of recognizing the free autonomy of any individual on a good (i.e., life). Indeed, there are numerous discursive lines that want us to think, in this matter, that humans have the ownership of life. The debate, when it arises, can be reduced legally, to merely agree if a person can own or not an asset (life) that supposedly belongs him or her and whether the scope of this freedom (availability) must be recognized and guaranteed [6]. Now, if life is an available good, and we have ownership over it, then: Why we cannot sell it or trade it in other areas? We should reflect on this question.

The truth is that the issue is much more complex and cannot be simplify to this extent. Inasmuch as life, to begin with, is not usually set in any legal ordinance as an available commodity. This, among other reasons, is why it is prohibited in general in all current systems the selling of oneself as slaves or why we can't sell our organs or voluntarily cut off parts of our body, among many other things. However, some would see on the law (absurdly simplified) a mechanism to can realize any individual expectation and to so justify individual moral choices at will. But, of course, the law is not an instrument that has as its goal to justify certain “moralizing” tendencies and therefore it should be accepted that, as said Andrés Ollero [7], “the law does not serve for everything”.

Usually, the discussion about these issues stems almost always from conventional the idea that there are certain rights belonging to disabled patients (experiencing the death process)

and that such rights must be protected and respected. However, in few cases the debate becomes transcendental to only consider the reality that affects, beyond the individual patient, debate that we consider necessary to understand the ontological reality to which we refer [8]. A consideration that usually is present in most health care professionals who care for such patients. This seems to be the reason why most of the current laws (as is the case, cited above, Act of 8 April 2/2010) fail to refer to medical professionals truly as facultative (those who are empowered to deal with the health of a person according to a “lexartis”). On the contrary, usually, they are requiring by those same laws, that establish the rules of duties and protocols that oppress them, making their work sometimes harder [9]. This situation, even without questioning what it is human life and whether it belongs to us, it is not therefore easy; therefore, the resolution of each of the multiple cases is impossible through a generalist law. It is even more difficult if the law is ideological. It would therefore necessary to listen and reflect with those who live in daily contact with such situations, being this, the only way to find appropriate solutions to resolve such delicate issues that this reality exposes.

In highly developed societies like ours death or how to die, has gained special prominence by the many possibilities offered by modern medicine (offering both the opportunity to artificially prolong life as the possibility of interrupting their advance). If we stop to think, most of humans living in the “third world” cannot consider this dilemma, itself only a middle-class bourgeois society can be bothered by it. A capitalist society like we live in has put us in this dilemma. Can we influence death? Can we kill for mercy? Should we prolong life? The question is this: as we have the means available that allow us to manipulate life and its process of extinction, can we or should we, do it? And if we do: With what aim, can we justify such intervention?

Beyond purely religious or moralizing speeches, we can observe with some concern, that the current debate is too focused on the justification or adequacy of an “assisted suicide worthy” as a solution to resolve the problem to those suffering from incurable and painful diseases. In contrast, little attention has been given to another important possibility (compatible with life), which is to alleviate the pain and providing dignify of life (and death), while the life continues, using techniques that are within our reach. The latter issue seems to us much more important, because it encourages scientific research into those areas. It seems clear (and it is humane) that anyone, in subhuman living conditions (i.e., where no assistance is given to dignify life through pain fighting care), one is tempted to end a painful life and perhaps (when there is no faith), so empty. But this should not lead us to conclude that the success, to solve these situations, necessarily consists in hastening death process, on the contrary, it should be to avoid pain and suffering. We therefore consider that it would be advisable, anywhere where they were to undertake normative regulations on this reality, to go for policies that promote the study and development of mechanisms for palliative care influencing the lives of patients facing their last period his existence, and for those who live that moment (we all must go through them, except those who suffer instant death) that they can do so with dignity. We favor strategies that promote research on palliatives; palliative care that offers greater peace and quiet to the terminally ill, and in doing so that allows them to accept

this period of life as it is, one more stage in "life". Although, unfortunately, in economic terms it is cheaper for any State (for this economic reason it is the preferred strategy) to resolve this issue supporting policies that promote death, paradoxically provoking debates about the "dignity of life".

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