

# Withdrawal of enteral nutrition in patients with persistent coma

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## Abstract

Persistent vegetative state is a clinical condition defined as a long period, from six months to one year, in a coma, which is only possible with the use of medical technology. In some countries, it is lawful for legal guardians to request the suspension of enteral nutrition for these patients, which certainly leads to death within a few days. There is a need for terminology that differentiates between therapeutic limitation, neglect and euthanasia. Therapeutic limitation arises at the moment of acute intercurrents affecting chronic terminal patients, while euthanasia is a request for controlled death. It is concluded, therefore, that the intentional withdrawal of nutritional support for these patients is an act of euthanasia.

**Keywords:** Brain injuries traumatic. Palliative care. Euthanasia. Gastrostomy. Hospice care.

## Resumo

### Suspensão de nutrição enteral a pacientes em coma persistente

Estado vegetativo persistente é condição clínica definida como período prolongado, de seis meses a um ano, em estado de coma, sendo somente possível com tecnologia médica. Em alguns países, é lícito aos responsáveis legais solicitar a suspensão de nutrição enteral a esses pacientes, o que certamente leva a óbito em intervalo de poucos dias. É necessária terminologia para diferenciar limitação terapêutica, negligência e eutanásia. A limitação terapêutica surge no momento de intercorrências agudas em pacientes crônicos terminais, enquanto a eutanásia é pedido de morte controlada. Conclui-se, portanto, que a retirada intencional de suporte nutricional a esses pacientes é prática de eutanásia.

**Palavras-chave:** Lesões encefálicas traumáticas. Cuidados paliativos. Eutanásia. Gastrostomia. Cuidados paliativos na terminalidade da vida.

## Resumen

### Suspensión de nutrición enteral en pacientes en estado de coma persistente

El estado vegetativo persistente es una condición clínica definida como un período prolongado, de seis meses a un año, en estado de coma, lo cual sólo es posible con el uso de tecnología médica. En algunos países, es lícito para los responsables legales solicitar la suspensión de la nutrición enteral de estos pacientes, lo que ciertamente conduce al óbito en un intervalo de pocos días. Se requiere la terminología para diferenciar lo que es la limitación terapéutica, la negligencia y la eutanasia. La limitación terapéutica surge al momento de las complicaciones agudas en pacientes crónicos terminales, mientras que la eutanasia es una petición de muerte controlada. Se concluye, por lo tanto, que la retirada intencional del soporte nutricional en estos pacientes es una práctica de eutanasia.

**Palabras clave:** Lesiones traumáticas del encéfalo. Cuidados paliativos. Eutanasia. Gastrostomía. Cuidados paliativos al final de la vida.

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Brain lesions may correlate with different disorders of consciousness, reflecting greater or lesser severity of brain damage, as well as their transience or permanence. Chronic disorders of consciousness are related both to chronic dementia, where the distinction between ageing and illness is not clear, and to acute brain damage, such as vascular accidents, trauma, situations that lead to anoxia (drowning, cardiorespiratory post-resuscitation, etc.)<sup>1</sup>. A recent and extensive and recent review of chronic disorders of consciousness has been carried out by Schiff and Fins<sup>1</sup>.

Undoubtedly, lesions that cause disturbances of consciousness raise complex bioethical questions. Permanent coma or vegetative state, among chronic disorders of consciousness, is a clinical context of lack of reaction or behavioural responses to environmental stimuli, while retaining autonomic functions and other brain responses<sup>2</sup>.

The persistent vegetative state is correlated with the loss of part of the brain, whilst still allowing the life of the individual for a longer period as it keeps active certain areas that control the most basic vital functions. In these cases, maintenance of life occurs mainly with the aid of technology to support vital systems, mainly mechanical ventilation as respiratory support and nutrition via feeding tube or gastrostomy, in addition to general hygiene care, repositioning in bed etc.<sup>3</sup>

Relatively long periods of time have been applied as criteria to define persistent vegetative state since 1994, with the publication of studies by the Multi-Society Task Force on the persistent vegetative state.<sup>4,5</sup> Three months after coma due to anoxia or 12 months after cranial trauma. In practice, Pessini<sup>6</sup> points out that, despite the chronicity inherent in the definition of the persistent comatose state, patients present several characteristics of end-of-life, and this intrinsic duality is at the root of bioethical debates about this clinical condition.

According to Clary<sup>7</sup>, the persistent vegetative state is a recent state in the medical history of humankind, since it is concomitant with the emergence, by the 1960s, of advanced technologies to support comatose patients. Until then, according to Turner-Stokes<sup>8</sup>, either the patient in that state recovered consciousness naturally or the patient died in a few days. This means that the persistent coma falls into the group of emerging situations in bioethics, according to the classification of Garrafa<sup>9</sup>.

Clary<sup>7</sup> also argues that the paradigm inherent in the definition of persistent comatose state is that,

in the absence of patient response, there is also an absence of perceptions and feelings. At the same time, he questions this paradigm, showing that up to a third of patients can regain some degree of response, albeit minimal, to environmental stimuli, and that the very definition of this state required nearly half a century of scientific debate for a more precise definition. In any case, there is always hope, although it is unlikely, that the patient in this condition will react to the environment and will eventually be able to establish some form of communication.

The world medical community was surprised in 2005 with the case of Terri Schiavo, an American in a persistent comatose state who passed away after doctors removed nutritional support and hydration after a lengthy legal process - the husband asked for the suspension of nutrition while the patient's parents wanted to keep the long term care. This emblematic case has brought to attention the bioethical discussion about the fact that, in some countries, it is lawful for the medical staff, upon request of those responsible for the patient in this condition, to suspend any and all nutritional support while maintaining the patient under deep sedation. Obviously, it is a measure that inexorably leads to death from dehydration in a few days<sup>10</sup>.

Debates about the withdrawal of nutritional support - called "artificial nutrition" - emerge at a time when the ethics of palliative care and the rejection of therapeutic obstinacy are being discussed. However, given the peculiarities of the patient in a persistent comatose state - absence of communication, total and absolute heteronomy, possible absence of sensorial and emotional perceptions, chronicity of the clinical picture, etc. - the bioethical world community has not reached consensus on the ethical validity of such a practice.

In short, according to Pessini<sup>3</sup>, antagonisms concerning the suspension of artificial nutrition are related to underlying values, that is, whether it is a practice of therapeutic limitation in the context of termination of life or whether, on the contrary, it is an ethically unacceptable form of end-of-life management that defies human dignity. Thus, this study aims to conceptualise whether the suspension of enteral nutritional support in patients in a persistent comatose state is a practice of therapeutic limitation or a form of euthanasia. It is not the objective of this paper to discuss whether such a practice is ethically acceptable or not.

## Method

The foundations of palliative care were researched in texts of national associations of palliative care, as well as in the works of theorists who publish on the subject. The discussion of the suspension of nutrition in patients with persistent comatose state was made by crossing the keywords “withdrawal”, “artificial nutrition” and “vegetative” in the Google Scholar search tool, in a period restricted to the last two years.

The articles were analysed sequentially as listed by the search program until no new subjects on ethics were found concerning the discussion. It is interesting to note that there was a preponderance of British authors because judicial proceedings are required to withdraw enteral support from the patients in the United Kingdom.

## Human dignity

The expression “human dignity”, as well as the words related to ethical values, carries at the same time an axiomatic characteristic, that is, it is understood on its own, and a polysemous aspect because the expression can, as matter of fact, be used even in diametrically opposed practices<sup>3</sup> such as, in this case, the maintenance or withdrawal of artificial feeding. According to Gomes<sup>11</sup>, the antagonism of the described situation can present the same foundation - human dignity - when approaching the problem from the perspective of the contradiction between the sacredness of life and quality of life that arises in extreme situations. In this way, there is an ambiguous concept: that of a dignified death. But death is precisely the only certainty in life and the one that most revolts human beings! Human beings try to control, in what suits them, their own biological processes. On one hand, this is expressed in a profound and radical way in the autonomy of terminally ill patients who have the right to decide to control their own death process. At the same time, there is ethical reference which considers that, since life is not deciphered, it is not ethically licit for human beings to decide the moment of their death<sup>12</sup>. According to Almeida<sup>13</sup>, this metaphysical point of view evidences, especially in patients in a vegetative state, that human dignity would be related to the principle of autonomy: in the loss of possibility of social interaction, reduced autonomy would result in the absurdity of generating a dignity that is also diminished. Pessini<sup>3</sup>

clarifies that dignity is an immeasurable value; there is no more or less dignity, but there is dignity or not.

The creation of the democratic state ruled by law rests on the concept of the dignity of the human being, a person-centred moral principle which is an inalienable attribute. Dignity remains present even more sharply in situations where apparently there is only suffering and various deficiencies<sup>13</sup>. If dignity was something that was valid and complete only in periods of complete health, disease would mean dehumanisation, loss of dignity, thus contradicting the fundamental human rights which seek to reinforce the concept of human dignity specifically in times of crisis - diseases, catastrophes, wars, epidemics. However, while human dignity is a framing of the democratic rule of law, the recent consensus of the European Society for Clinical Nutrition and Metabolism (ESPEN) was based only on technical principles of medical practice, with no reference to human dignity<sup>7</sup>.

## Therapeutic futility

Therapeutic futility is defined by Biondo, Silva and Secco<sup>14</sup> as the medical practice of adopting invasive and therefore painful and uncomfortable treatments that only prolong the agony of the terminal patient. However, this concept has gradually expanded, including any kind of medical treatment, according to the general clinical context of the patient. Porta i Sales<sup>15</sup> differentiates the concept of therapeutic futility, stating that it does not apply to acute patients (trauma, serious infections, vascular accidents, etc.) that may eventually present a serious evolution of their clinical condition. Therapeutic obstinacy is not an applicable concept for this situation even if biomedical technology is not effective for these patients. The idea of massive investment of technologies as a futility is a concept that applies only to patients who are already chronically ill.

Diniz<sup>16</sup> distinguishes “painful treatment” from “medical torture” in the following way, using the words of the parents of a chronically and seriously ill child: if an invasive treatment presents potential for healing or improvement, it is a painful treatment that they must endure. But in the absence of any prospect of even a partial improvement, “therapeutic futility” or “therapeutic obstinacy” become only euphemisms for “torture.”

Simone<sup>17</sup>, as well as Biondo, Silva and Secco<sup>14</sup>, list the concepts of dysthanasia, futile treatment,

useless treatment and therapeutic obstinacy in the same synonymy. In addition, Taboada<sup>18</sup> and Alonso<sup>19</sup> relate these concepts to the value of dignity at the moment of death. For that reason the ideal of a good way of dying would be incompatible with the growing therapeutic obstinacy. Thus, according to Nunes<sup>20</sup>, the hyper medicalisation of death, in which the cold and institutional relationship with the patient is intensified, ends up becoming a generalised practice, opening up deep ethical questions.

Burlà and Py<sup>21</sup>, reflecting on the meaning of this concept of natural death, or orthothanasia, for clinical practice, conclude that there is not exactly a good way to die, much less that death itself has any dignity. Death is the inexorable event that most arouses the indignation of human beings, and when it is close, it seriously destabilises the psychic structure of the individual. This paradox is synthesised and well explained by Taboada<sup>18</sup> for whom, given the reality of medicalisation of the place of death, ethical, legal and technical issues must be directed to the care of terminal patients. That is, abstract discussions about abstract ethical values are achievable and palpable in the idea of a good medical management of end-of-life.

According to Kovács<sup>22</sup>, this management is based on the inherent nature in all medical treatment, which has a double effect: at the same time, there is always a positive (or desirable) and negative (or undesirable) aspect, which can only be balanced in terms of risk-benefit for a specific patient. Thus, futility is a relative attribute, and knowing the possibilities of a given treatment - whether there is a prospect of actual cure or only relief - is the basis for legitimising the characterisation of a particular therapy as futile or necessary. Moreover, the futility / necessity dichotomy refers to the valuation of values and is therefore a moral judgment. But such a judgment must also be sufficiently substantiated by statistical data of similar previous situations that allow the inference of expectation of survival, incidence of serious side effects, chance of success, etc.

The National Academy of Palliative Care defines a terminal patient as one whose diagnosis and time course of disease progression would allow, with 95% of certainty, to expect death to occur between three and six months<sup>23</sup>. Of course, this kind of mathematical range should not be interpreted in an absolute way, but in the case of patients in a persistent vegetative state, artificial feeding certainly prolongs life for an indefinite period and over six months. In fact, considering the length of

time necessary to classify a clinical condition as persistent vegetative state, the artificial feeding itself becomes one of the therapeutic resources that allows the existence of this clinical condition.

Calderón, Pazitková and Naranjo<sup>24</sup>, as well as Nunes<sup>25</sup>, list the most typical situations regarding therapeutic limitation: The treatment of a given patient should be suspended if it clearly shows more deleterious effects than benefits. The treatment should be waived if the expectation of the risk / cost / harm is greater than the eventual benefit. No interruption is allowed if treatment is bringing comfort to the patient. However, these distinctions are not always obvious what continually motivates biomedical research and ethical reflections. Essentially, the most legitimate way to support decisions about therapeutic limitations is to dialogue with the patient and/or those responsible for the patient.

### Palliative care

The dictionary lists *attenuate* or *to relieve* as synonyms of the word *palliate*. But since synonymy is never perfect, the word *palliative* also has connotations of *incomplete* and *temporary*. For this debate it is necessary to delimit that palliation is any therapeutic measure that results in permanent or temporary relief of suffering. Symptomatic relief is an essential part of any therapy. It is not just for terminally ill patients. As an example, upper respiratory tract infections are self-limited but patients receive treatment for the relief of symptoms.

Palliative care, as defined by the World Health Organisation in 2002, is *an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering*<sup>25</sup>. The ethical principles of palliative care, according to Floriani and Schramm<sup>26</sup>, are situated between euthanasia and therapeutic obstinacy, rejecting both extremes. In refusing therapeutic obstinacy, palliative care seeks only to alleviate symptoms that affect the end-of-life process.

Palliative care services are indicated provided that there is a diagnosis of predictably fatal disease, such as heart failure, neoplasias etc. However, these services focus on patients who are already in terminal condition of life. They are therefore patients with reduced competence and, in this way, with reduced autonomy. Palliative care reveals that all health care

has a protective aspect, protecting human dignity, and although the dialogue with the person responsible and/or family of the patient is the ethical pillar of therapeutic limitation, their absolute autonomy in decision making is not allowed. There are ethical and professional responsibility principles to be followed<sup>13</sup>.

This is because, as Leone<sup>27</sup> points out, if there was only mutual respect in human relations, it would not make sense to elaborate norms and laws that would protect disabled patients and minors. As a rule, caregivers seek the highest good for the people under their responsibility, but exceptions to that are often enough to motivate State measures such as guardianship and protection. On the other hand, caregivers are also vulnerable people, exposed to all kinds of adversity, and it is not enough to protect the patient against eventual malicious caregivers, but to sustain and protect the social / family environment of all those who are part of the situation.

Therapeutic limitation should not be decided abruptly or urgently. It should be planned according to the diagnosis of fatal chronic disease. The doctor will always have freedom and responsibility to start treatment, but when it comes to therapeutic limitation, the decision must be previously discussed and programmed. The more guidelines and studies regarding the clinical course of diseases and the impact of available therapies, the safer this program will be<sup>28</sup>.

There are several authors in the literature who use the term “passive euthanasia” in an attempt to relate therapeutic limitation to immediate death and reduction of life expectancy. However, the principles of palliative care are legitimised on the statistical study of Tan et al.<sup>29</sup>, which indicates the opposite, that is, patients present both better quality of life and prolonged life with adequate and less obstinate care.

The explanation of this finding is based on the double effect nature of treatments: considering the extreme fragility typical to the context of terminability, it is more important to not expose the patient to side effects of a treatment than to try some therapeutic benefit. Although Feltman and colleagues<sup>30</sup> consider that any medical treatment can be discussed having in mind the possibility of waiver or suspension, the most ethical discussions have been about respiratory support or mechanical ventilation and artificial nutrition.

Morrison and Kang<sup>31</sup> agree with Rapoport and colleagues<sup>32</sup> when they consider that it is necessary to create a vocabulary able to distinguish nuances between therapeutic limitation and negligence

crime in situations involving new technologies. Thus, for Morrison and Berkowitz<sup>33</sup>, the word *euthanasia* must refer to situations that meet two criteria: 1) an explicit request for death; and 2) measures taken during the inter critical periods of the patient. Thus, only in situations of crisis or exacerbation the concept of therapeutic limitation can be affirmed.

In more advanced and more complex discussions, Feltman et al.<sup>30</sup> and Wilfond<sup>34</sup> recall that even minimally invasive relief care - such as tracheostomy or gastrostomy - are not a priori obstinate but may produce and create new complications, and the treatment of these complications may configure therapeutic obstinacy.

Diekema and Botkin<sup>35</sup> and also Ambler<sup>36</sup> assume that nutritional support would be essential care only if the patient can swallow and / or resume such capacity and therefore the suspension of this support would be ethically acceptable in the case of persistent vegetative state. However, the authors do not clarify the situation of patients who ultimately lose their swallowing ability but maintain a relatively preserved level of consciousness.

In turn, the British and American legal doctrine leave that consideration to those responsible for the patient. Leeuwenburgh-Pronk and collaborators<sup>37</sup> brought up nutrition withdrawal for discussion and pointed out that the reason for the request of nutrition withdrawal is not that nutrition is maleficent, but that the patient’s overall clinical condition is very distressing.

Morrison and Berkowitz<sup>33</sup> review artificial nutrition and recognise that there are situations when nutrition is harmful to terminally ill patients. A typical example was published by Hidayat et al.<sup>38</sup>, in which a young woman suffered from a terminal cancer that caused her to feel a great hunger and desire to eat but whenever she fed herself, she suffered with vomiting what dehydrated her. Turning to patients in persistent coma, Wellesley and Jenkins<sup>39</sup> report that at least half of US physicians do not consider the suspension of artificial nutrition ethically acceptable. In Europe, DeVictor and Latour<sup>40</sup> point out an ethical tendency to withdrawing artificial nutrition according to circumstances, although it is difficult for medical teams to propose withdrawal.

## Final considerations

None of the articles searched<sup>41-49</sup> considers that nutritional support is measured as

uncomfortable, painful or unacceptable for these patients. This contrasts with previously consolidated knowledge about other groups of users, such as cancer patients<sup>50</sup>, to whom enteral nutrition may be correlated with worsening of the clinical condition in general<sup>51</sup> and may require adjustments in their dietary composition<sup>51,52</sup>. It could even be better for the patient to have the nutritional support suspended as a sign of health care with dignity at the end of life<sup>50,51,53</sup>.

Nevertheless, the values listed to justify nutritional suspension in patients with persistent vegetative coma are based on quality of life, best interests, family burden, subjection to diverse clinical interurrences, patient autonomy, legitimacy of the person responsible in representing the patient in its autonomy and *natural* course for the death of a seriously ill patient. The legal language first attempts to define whether nutritional support is medical treatment or simple health care, because if it is defined as *medical treatment*, then its withdrawal or renunciation is likely to be discussed. On the other hand, if nutritional support is understood as simple health care, it is characterised as something that can not be denied to the patient.

Under this argument, Veshi<sup>48</sup> refines the debate by raising the gap between nutrition through tube feeding and nutrition by gastrostomy. Since the passage of a nasogastric tube is a simple procedure and can be performed even by relatives, it can be considered as basic health care, which could not be denied or withdrawn. Gastrostomy, on the other hand, depends on a surgical procedure, which can only be performed by physicians and, being considered as treatment, could, under certain circumstances and given certain protocols, not be carried out.

Jox et al.<sup>42</sup> conclude that most relatives of patients in persistent coma do not request withdrawal of nutritional support. In their survey, the notion of human dignity is made clear in the constant hope that the patient will return, at least in part, to consciousness and try to establish communication, even if minimal.

Marcus, Golan, and Goodman<sup>46</sup> compare the nutritional approach in elderly patients with advanced dementia and in adult patients in a persistent comatose state. The clinical contexts are somewhat similar, but each one has its own peculiarities and therefore necessitate different ethical basis.

In the final stages of dementia, the patient refuses to eat, i.e., there is no impediment to

swallowing, but a cognitive problem that causes the patient to not feed or hydrate. Although the patient feels comfortable with this decision, the patient ends up dying in the period expected for a person who is in total fasting.

Thus, it is discussed with regard to end-of-life medical care whether or not the initiation of enteral nutrition by gastrostomy is mandatory or if this artificial feeding can be characterised as therapeutic obstinacy. However, this condition diverges from the persistent comatose state, since, by definition, this state is definable only after a relatively prolonged period, which would only have been possible due to the use of nutritional support.

Kitzinger and Kitzinger<sup>44,45</sup> make explicit that the request for withdrawal of enteral nutrition has the purpose of the patient's foreseeable death, that is, euthanasia. It is clearly a request for death, which, in the words of Druml et al.<sup>47</sup>, would be a *natural* death. Here we have an essential anthropological understanding, applied to bioethics, that there is not exactly anything *natural* in human experience: the construction of the world view, the patterns of interpretation and the interaction of the human being with the outside world, even in its last moments, is intermediated by the cultural construct of its social group. Thus, the term *natural death* does not find support in the context of patients in persistent coma, since the clinical condition itself derives exclusively from the use of medical technology.

The scope of the discussion about withdrawal of enteral nutrition goes beyond the sphere of palliative care and enters the field of euthanasia, which presents a different (favourable / unfavourable) ethical grounding. While the ethical foundations of palliative care are bioethical consensus, euthanasia presents legal acceptance restricted to a few countries, and has even become taboo. Therapeutic obstinacy is related to the discomfort that the treatment itself causes, in the context of terminality of life.

This conceptual confusion is deleterious to the improvement of palliative care, since they are evoked to justify euthanasia practices. Palhares, Santos and Cunha<sup>54</sup> indicated the need to define therapeutic limitation practices, differentiating, for example, the ethical and legally valid therapeutic limitation of a medical malpractice.

In any case, the practice itself can be defined only in the clinical context. Thus, therapeutic limitation - renunciation or withdrawal of invasive

treatments - can be evoked only in the presence of clinical intercurrents. That is, the withdrawal of nutrition support from a patient in a persistent coma can not be considered a therapeutic limitation, since it is done in a planned and intentional way in the moments of clinical stability of the patient.

In the case of the United Kingdom, an interval of 9 to 14 months has been reported to authorise the withdrawal of artificial nutrition in court<sup>44,45</sup>. If, by ethical consensus, the therapeutic limitation is imposed when the life expectancy of the adult patient is less than six months, the practice of withdrawal of nutritional support is definitely not made in the context of therapeutic limitation in acute intercurrents, but as a planned form to terminate the patient's life.

It may be argued whether or not it is permissible for the person responsible for a patient in persistent coma to explicitly request the patient's death, given the chronic context of mourning, burden and suffering of this situation, but it is not permissible that there is any terminological confusion between the practice of euthanasia and therapeutic limitation. This confusion does not allow a clear and precise discussion about the best way of managing a patient's end-of-life medical management. This lack of distinction, seeing euthanasia as an act of

therapeutic limitation, may undermine the very improvement of palliative care, since there will always be a shadow of doubt whether such palliative care is aimed at the preservation of human dignity through therapeutic limitation or whether it is a simple euphemism for euthanasia.

In any case, it might be beneficial for these patients that the word *euthanasia* is clearly mentioned, so that the slow predictable process of death by starvation and dehydration could be replaced for a more immediate method. After all, euthanasia is one of the expressions of human desire to control biological processes, in the case of death, in the most gentle way possible.

As it has been done until now, the suspension of nutritional support ends up becoming a ritual of end-of-life care, which attempts to sublimate and conceal what would actually be euthanasia practice. What could be a simple procedure becomes a slow and costly agony, with administration of sedatives and analgesics and even laboratory tests, as it happened in the case of Terri Schiavo. In conclusion, the authors consider that the planned and intentional suspension of artificial nutrition to patients in a persistent comatose state is a form of euthanasia and should not be called a therapeutic limitation.

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**Participation of the authors**

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