

# Therapeutic limitation for children with severe brain malformations

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## Abstract

Brain malformations may present themselves in different forms, from mild to severe, which can be lethal within a few hours after birth. Based on a systematic review of literature, it was verified that, although theoretically suspending or withholding treatment are ethically similar, in practice, such equivalence is not perceived either by doctors and nursing assistants or by the general population, who tend to more comfortably accept the withholding rather than the withdrawal of treatments. The dialogue with parents is the procedure that legitimizes medical initiatives when proposing therapeutic limitation. In conclusion, severe brain malformations result in an end of life context, in which bioethical principles of palliative care apply and in which the limitation of respiratory support is the main dilemma to be faced in the final moments of patients' lives.

**Keywords:** Hydrocephalus. Microcephaly. Medical futility. Corpus callosum. Chromosomes-Pathology.

## Resumo

### Limitação terapêutica para crianças portadoras de malformações cerebrais graves

As malformações cerebrais congênitas podem se apresentar de forma leve ou grave, podendo ser letais mesmo poucas horas após o nascimento. A partir de levantamento bibliográfico sistemático, verificou-se que, embora em tese sejam eticamente semelhantes suspender e renunciar a tratamento, tal equivalência não é percebida na prática por médicos e enfermeiros assistentes, nem pela população em geral, que tende a aceitar mais confortavelmente a renúncia que a suspensão de tratamentos. O diálogo com os pais é o procedimento que legitima a iniciativa médica de propor limitação terapêutica. Em conclusão, as malformações cerebrais graves resultam em contexto de terminalidade de vida, em que limitação ao suporte respiratório é o principal conflito enfrentado e ao qual se aplicam princípios bioéticos dos cuidados paliativos.

**Palavras-chave:** Hidrocefalia. Microcefalia. Futilidade médica. Corpo caloso. Cromossomos-Patologia.

## Resumen

### Limitación terapéutica para niños con malformaciones cerebrales graves

Las malformaciones cerebrales congénitas pueden presentarse desde formas leves hasta formas graves, pueden ser letales pocas horas después del nacimiento. A partir de una revisión bibliográfica sistemática se verificó que, aunque teóricamente suspender o reiniciar un tratamiento es éticamente semejante, esta equivalencia no es percibida en la práctica ni por los médicos y enfermeros asistentes, ni por la población en general, que tiende a aceptar más cómodamente la renuncia que la suspensión de los tratamientos. El diálogo con los padres constituye el procedimiento que legitima la iniciativa médica de proponer la limitación terapéutica. En conclusión, las malformaciones cerebrales graves dan lugar a un contexto de terminalidad de la vida, en el cual se aplican los principios bioéticos de los cuidados paliativos, y en el que la limitación del soporte respiratorio es el principal conflicto que se enfrenta en los momentos finales de la vida del paciente.

**Palabras clave:** Hidrocefalia. Microcefalia. Inutilidad médica. Cuerpo caloso. Cromosomas-Patología.

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Declararam não haver conflito de interesse.

The history of what may be called a good, or “happy”, death probably began in Suetonius’s work “The Lives of the Twelve Caesars”, dating from the second century AD, which contains a description of the tranquil, swift death of Emperor Augustus<sup>1</sup>. This is a term that has been adopted by the medical community, which aims to minimize the suffering within the context of the end of a person’s life. The right to life is guaranteed by human dignity; however, in a situation involving terminal illness, the tension that is inherent to the topic itself is evident and is indicative of the need to continually improve the technical and ethical aspects of such situations in order to better manage death in medical terms<sup>2,3</sup>.

Medical responsibility is a principle of the utmost importance not only in terms of bioethical analysis, but also in taking the decision to bring forth elements that highlight the asymmetry between doctor and patient and the protection of this relationship under law. Unforeseeable accidents and uncontrollable maladies exist, which arise from situations that involve an inexorable progression, independent of the efforts of the medical professionals and staff, and which are related to the intrinsic mortality of every living being<sup>4</sup>. Caring for terminally ill patients increases the responsibility of the health care professional, who finds himself weakened when he administers such care to patients due to the inevitable association between responsibility, risk and guilt, especially regarding the possible non-compliance of the professional with ethical and legal obligations<sup>5</sup>.

The complexity of events that are involved with terminal illness represents a challenge for professionals in this field<sup>6</sup>. This is a paradox, which, in every sense of the word, fragments the understanding of the bioethical principles in a frontier realm, providing a stage for different ethical and moral, bioethical and deontological, regulatory, legal and administrative discourses.

The terminal nature of life is an even greater encumbrance when it involves children that have incurable chronic diseases that will not allow them to live for very long. In other words, when, during the life cycle of an individual, birth and death become temporally proximate. Congenital malformations are examples of these clinical conditions, and, in general, such deformities can be expressed in various degrees of severity, from relatively mild, which will not significantly reduce the individual’s life expectancy, to more severe forms, which will become lethal only a few hours after birth.

Children that have cerebral malformations that evolve into a terminal clinical condition evoke moral and, therefore, bioethical dilemmas that can be classified at the crossroads between fundamental

concepts found among neuroethics, the ethics involved in palliative care and the ethics of pediatric care. These children are, generally, submitted to treatments that are clearly intensive and obstinate, but there are also situations in which the obstinacy is not so obvious.

In the vast majority of countries, pediatric care is not characterized by the heteronomy of the child, that is, its legal incapacity to decide for him or herself; the child must be represented by a responsible adult, which is generally the parents or some other representative that has been legally appointed. However, there are bioethical issues regarding the limits of this protection and the margin of parental decision-making in light of potentially lethal clinical conditions, especially when differences arise between the desires of the parents and the duties of the medical staff.

The treatment of terminal patients requires the application of health care practices that are based on there not being a chance of curing the patient<sup>7</sup>. The dignity of human life which has passed on must be respected, and, because of this, the decision to perform adequate treatment to maintain the life of a patient and mitigate suffering in a manner that does not increase the individual’s pain and discomfort are ethical issues that are relevant when one is treating children with severe brain malformations. In each situation, for each patient, circumstances may arise in which it becomes clear that therapeutic obstinacy is being undertaken, but there will also always be situations where the limits are imprecise, where the best path to take is not clearly visible<sup>8,9</sup>.

Deep geopolitical differences exist between countries where palliative care and therapeutic restrictions have been legally implemented and have become both routine and ethically recognized in medical practice, and those countries where terminal care tend to be more obstinate, which make constant use of intensive technologies<sup>10</sup>. Brazil is considered to be at an intermediate stage because, despite the fact that therapeutic obstinacy has not been set forth in the country’s legal code, ethical standards have already been developed and submitted by the Conselho Federal de Medicina (CFM) (Federal Council of Medicine) with respect to the limitation of therapy when dealing with patients that are terminally ill.

Considering the above, and based on a review of the literature, the present article has the following objectives. 1) to analyze the peculiarities that exist in addressing palliative care and therapeutic restrictions in caring for the health of children that possess brain malformations; 2) to identify the principal invasive therapeutic procedures in caring for the health of these children; 3) to delimit the ethical and conceptual difference between “obligatory care” and

“therapeutic obstinacy” when caring for the health of children that have brain malformations; and 4) to analyze the bioethical boundaries of the decisions of those that are responsible when faced with the heteronomy of these children.

## Methodology

A systematic revision of relevant journal articles was conducted, during which these articles, in accordance with Marconi and Lakatos<sup>11</sup>, had their sources identified. The articles themselves were then located, compiled and cataloged. To identify the sources, indexation catalogs were used from the ISI Web of Science, the Biblioteca do Centro Latino-Americano e do Caribe de Informação em Ciências da Saúde (Bireme) (Latin American and Caribbean Center on Health Services Information), the Scientific Electronic Library Online (SciELO) and Google Scholar. Initially, a search was conducted by cross-referencing the keywords “ethics”, “palliative care” and “child”. The system returned more than 20 thousand possible bibliographic references. In order to narrow down the total number of articles, researchers opted to select articles that were published up to 2015.

In light of this result, researchers attempted to refine the search by adding “*and not cancer*”, since the cases that are the focus of this paper are not related to oncology. As such, the search attained the objective of focusing on the issue of cerebral malformation/lesions. The sources that were taken from each indexation catalog were then cross-referenced. The sources were listed and searched for within the open access portals known as Periódicos Capes and Research Gate, in addition to a direct search that was conducted using the Google search tool. Through the cataloging of each source, data was extracted regarding the illness that gave rise to the child receiving palliative care; treatments and procedures that are characteristic of therapeutic obstinacy; bioethical limits of the exercise of heteronomy by the responsible adult; and ethical and legal consequences and restrictions that arise when recommending the use of palliative care techniques. The data was compared in order to reveal which thoughts, fundamental aspects, concepts and paradigms the authors agreed and disagreed upon. This process of analyzing the data was conducted in accordance with the *feedforward* model, i.e., the analyzes that had already been completed provided guidance for the following analyzes, and, as a result, some papers that addressed pathologies that did not involve the brain were maintained in the sample because they discussed bioethical issues that were relevant to the subject matter.

## Results and discussion

### Bibliometrics

The systematic review of literature found 119 papers, of which 67 were obtained in their entirety<sup>12-78</sup>. The clinical cases that were studied were related to a variety of disorders; however, a preponderance of neurological disorders was encountered, which elucidates how neuroethical issues stand out within the field of pediatric palliative care. The disorders that were identified included: severe cerebral palsy<sup>12</sup>; severe heart failure due to inoperable cardiomyopathy<sup>16</sup>; spinal muscular atrophy<sup>27,52</sup>; Duchenne muscular dystrophy<sup>31,50</sup>; persistent coma due to the accidental lesion of a patient already suffering from incurable intracranial neoplasia<sup>32</sup>; respiratory insufficiency due to pulmonary hemosiderosis<sup>36</sup>; Down’s Syndrome associated with degenerative encephalopathy<sup>42</sup>; kidney transplant and persistent coma due to accidental trauma<sup>44</sup>; trisomy 18 with operable heart disease<sup>45</sup>; terminal cystic fibrosis<sup>45</sup>; inborn error of metabolism with persistent coma<sup>47</sup>; and Proteus syndrome<sup>69</sup>.

The papers that were researched gave a well-founded day-to-day overview of the bioethical conflicts regarding palliative care techniques that become standard practice, i.e., which have become associated with therapeutic restrictions. Therapeutic restrictions therefore represent extreme cases of palliative care techniques with respect to which bioethical conflicts have become significant. In essence, the ethical-legal basis for this issue, according to Lago et al.<sup>42</sup>, resides in the fact that terminal medical care techniques, in the final analysis, become a public health care issue.

### Overview of pediatric palliative care techniques

The papers that were selected and analyzed were in agreement that the ethical dilemma surrounding therapeutic restrictions has emerged in conjunction with the significant progress that has been made with respect to biomedical technology. A situation of inertia arises for the doctor and for the judicial framework of society when the full breadth of biomedical technology is put to use indiscriminately, despite the deleterious effects that are inherent to vital life support mechanisms, mainly those that are the most invasive. Regarding this aspect, Sayeed<sup>64</sup> states that poorly written laws, which are also in disagreement with the reality of clinical practices, stagnate the resolution of serious issues and worsen the possibilities of treating the group that is most at risk - namely, patients receiving terminal care.

Mercurio et al.<sup>48</sup> color coded a set of countries as follows: green, indicating those countries that have

explicit laws that recognize the need to impose therapeutic restrictions; yellow, indicating those countries in which the situation is not defined, but tend to accept such restrictions; and red, indicating those countries where any discussion of the subject is rejected. Durall et al.<sup>21</sup> provides examples and states that, in Russia, discussion of the issue is not allowed and the subject of therapeutic restrictions may not be publicly addressed. As a result, the majority of the bioethical debates that were encountered were submitted by authors from countries in which therapeutic restrictions have already been incorporated into the country's laws, so that conflicts are shown to contain a higher level of complexity.

In theory, according to Pelant et al.<sup>53</sup>, adequate palliative care services avoid the need for hospitalization, isolation and unnecessary invasive techniques with respect to terminal healthcare procedures. However, Lago et al.<sup>42</sup> warned that, with respect to the pediatric age range, terminal care procedures have been undertaken more frequently in intensive care units (ICUs). Such cases generate clear ethical conflicts, since ICUs are structured to provide intensive care procedures, whereas terminally ill patients require palliative care and therapeutic restrictions.

Regarding this issue, a study by Ramnarayan et al.<sup>59</sup> showed that adults who are nearing the end of their lives prefer to die at home, whereas terminally ill children tend to pass away in a hospital environment, and, most frequently, in ICUs, in which a condition of therapeutic obstinacy is in place. Accordingly, Rezzónico<sup>62</sup> proposes that terminal care techniques should be based on the refusal of the practice of therapeutic obstinacy, i.e., in the refusal of the monolithic use of medical technology even when it is clear that the patient is going to die shortly thereafter. Generally speaking, treatment procedures that are painful and ineffective are rejected or suspended<sup>12,78</sup>; however, this is not to say that the patient is ever abandoned and does not receive care. The health care professionals simply no longer make use of advanced medical techniques and, in lieu of these procedures, administer medications that alleviate the patient's symptoms and perform basic care on the individual. In other words, a terminal patient that is receiving palliative care procedures should not be submitted to an ICU. Hospitals make other sectors available to such patients – such as the infirmary, or a room, or a day-bed – which are more appropriate for the care of terminally ill individuals.

Morgan<sup>49</sup> compares the recommendation for therapeutic restrictions with respect to adults – which, by convention, considers six months to be a statistically foreseeable time period for the onset of death, which is assumed to be an initial condition

for the refusal or suspension of treatment – with the procedures that are adopted for the patients that are within the pediatric age range, whose statistically foreseeable time period for the onset of death has not been established by the medical community.

Leeuwenburgh-Pronk et al.<sup>43</sup> note that the heteronomy of the child exists for the purposes of his protection, due to the immaturity that is inherent to this period within an individual's life cycle. When this essential principal is set before the case of a child that suffers from a chronic disease which has severely reduced his life expectancy, the ethical and legal conflicts that arise regarding therapeutic restrictions reflect a conflict of interests between the values of the sacrosanctity of life and the maintenance of one's quality of life. Both are expressions of overall societal values which only manifest themselves in practical terms within real-world cases. Geller et al.<sup>32</sup> have reaffirmed this point of view, since the conflict becomes even more powerful with respect to children.

In such cases, the conflict regarding which value should prevail is intensified. One can either take into account giving the child another day of life, which may be priceless; or, on the contrary, consider at what point the lack of quality of life should enter into the assessment. As an example, Klein<sup>41</sup> mentions the case in which an infant who has holoprosencephaly with severe respiratory morbidity has undergone prolonged treatment at an ICU, and is therefore in a situation in which therapeutic restrictions would be recommended. However, in unexpected fashion, this baby recovered demonstrably well after being discharged and developed into a toddler of pre-school age without presenting any severe new health issues.

Cases such as this one raise the issue of expected time limits regarding the imposition of therapeutic restrictions; should such restrictions be proposed in situations where death is expected to occur within six months, such as is the case with adults? Or should other factors be taken into account, such as the probability of survival, and up to what age – ten years of age, adolescence or onward towards adulthood should be taken into consideration? The literature shows that the issue is still open.

### *To suspend versus renounce treatment*

The majority of the papers that were evaluated address the ethical-legal debate regarding the difference between suspending and renouncing the use of treatment techniques. The theoretical conclusions that were reached by the authors state that the suspension or refusal of certain treatments is ethically equivalent; however, in practice, doctors, nurses and the general population believe that it is more

acceptable to renounce the use of these treatments than to suspend them.

Tsai<sup>71</sup> states that the evaluation of the beneficial and deleterious effects of suspending treatment has already been made possible. As a result, the suspension of advanced life support techniques brings with it a foreseeable estimation of when death will occur, and that the perception of this expectation would be tantamount to equating the suspension of treatment with the concept of euthanasia. In this respect, legally speaking, the term “euthanasia” is applied when an explicit request has been made by the patient to allow his death to occur, whereas the suspension of inefficacious and obstinate treatment procedures in fact constitutes palliative care measures. In practice, the act of renouncing the use of advanced medical treatment implies the substitution of more invasive treatment for other procedures that, although they may be less efficacious, result in the perception that the patient’s life is ending “naturally”<sup>71</sup>.

An elegant resolution of this conflict of values can be found in the statistical work that was completed by Tan et al.<sup>67</sup>, in which these researchers established, in mathematical terms, that both the perception of common sense and the ethical viewpoint are correct. The authors present a Kaplan-Meier survival curve for groups that consist of patients that are submitted to a “refusal” and a “suspension” of treatment. In the initial phase, both groups presented the same indices of mortality; however, once the initial phase had been surpassed, the “refusal” group surprisingly presented greater survival rates than the “suspension” group. In other words, when certain invasive treatments are suspended or are renounced altogether, the event of death will be predictably more immediate in patients whose conditions are more serious. However, a significant proportion of patients may survive longer, indefinitely - from a few days to many weeks, if, instead of intensive and invasive procedures, these patients receive adequate palliative care techniques.

In any case, Klein<sup>41</sup> notes that, when treatment is suspended and death does not occur shortly thereafter, parents tend to question whether or not the diagnosis of terminal disease was truly correct. As a result, decisions involving therapeutic restriction are frequently overturned, which heighten bioethical conflicts about the breaching the doctor-patient bond of trust, which is perfectly understandable in light of the significant subjective nature of the anxiety and responsibility that befalls the parents in the face of their child’s imminent death. This breach of trust highlights the deep desire of the parents in removing,

or at least protecting, their child from suffering during their final moments.

### *Ethical procedures in deciding to restrict therapeutic procedures*

Forty-six of the papers that were evaluated mentioned the issue of the decision-making process that is involved in restricting therapeutic procedures. The issue of the child’s dependence and their incapacity to express their desires fully has always been presented not as a barrier to the implementation of therapeutic restrictions, but as a factor that generates special cases of ethical conflict. For purposes of comparison, Siegel et al.<sup>66</sup> have stated that child euthanasia, which is legal in Holland and Belgium<sup>79</sup>, is a procedure that is broadly addressed within the legal codes of these countries, within which the public prosecutor evaluates the decision-making process with respect to the exercise of legal precepts. Such instances do not constitute an analysis of merit, but merely a process of establishing that each of the formal phases of the process were complied with.

In light of this fact, Morrison and Kang<sup>51</sup> established that the decision to restrict therapeutic procedures in an ICU, albeit a difficult one, has already become commonplace, so that the medical staff, who understand and have had extensive daily experience with the case, are responsible for the decision-making process. In other words, the authors defend that institutional ethical committees are an essential requirement, but argue that their role should be to act as a supervisory committee for resolving conflicts as they arise.

In each of the texts that were obtained, the value of maintaining communication with parents is clearly evident as a procedure that legitimizes the implementation of therapeutic restrictions. An additional consensus is that the implementation of therapeutic restrictions must be established by the medical staff; such a suggestion only arises from the parents in limited cases. In summary, the literature review shows that proper communication and decision-making procedures and conditions should be in place. Firstly, the medical treatment staff, consisting of doctors, nurses and physical therapists, should, during their daily visits, agree amongst themselves that the implementation of therapeutic restrictions is the best option for that patient. As a result, the parents of the child are invited to meetings with said hospital staff, which should occur in a room that is appropriate to this end.

During the first meeting, the subject is addressed and time is given for the parents to reflect on

the issue; in a subsequent meeting, the decision to implement therapeutic restrictions is taken. In some cases, parents feel insecure, thereby making it necessary to hold more meetings. Some authors<sup>14,75</sup> have described open and honest techniques of communication with the parents of terminally ill children. The issue of communication has been under debate since at least 1969, when Philip Evans and Cicely Saunders<sup>22</sup> confronted the culture of the time with respect to the death of children. Evans wrote that the doctor presented a strong, involuntary, emotional reaction to the point of weeping with the parents that lost their child, while Saunders emphasized the necessity of showing empathy, albeit with a certain emotional detachment, to make it possible for the family members to receive adequate support for their loss. Even now, not only the doctor but also nursing professionals need to know how to emotionally deal with the terminal nature of life within the field of pediatrics<sup>49</sup>, which strengthens the argument for the need of these professionals to conduct regular clinical visits to ICUs.

The implementation of therapeutic restrictions is not an untimely measure, nor is it a matter of urgency; it is a decision that is taken in stages in light of the chronic nature of the situation. In other words, the doctor, in facing a critical situation, has the responsibility and ample freedom to prescribe and initiate treatment procedures. However, when dealing with the issue of therapeutic restrictions, the decision-making process must be shared with the parents or with those that are responsible for the child. The implementation of therapeutic restrictions is, above all, a decision that is taken within the institution by the medical treatment staff; such a decision cannot be left to the discretion of the medical chief of staff or doctor that is on-call.

The literature review revealed that two legal stances have been established that identify cases in which therapeutic restrictions may be considered legitimate. In the United States, such restrictions are legal, albeit profoundly dependent upon the agreement that is reached with the parents. The decision of not resuscitating the child, for example, must be stated in writing and signed by the responsible adults. In other countries, such as France and Japan, the paradigm of non-objection is adhered to, which is to say that the medical staff proposes the adoption of therapeutic restrictions that are implemented should the parents not object. For some scholars<sup>42,17</sup>, in light of the emotional vulnerability that the families are subjected to, the non-objection paradigm is a form of alleviating the weight upon the parents of having to make that decision by transferring the burden to

the health care staff so that the parents do not, in the future, feel guilt for having made that decision.

The more enlightened legal provisions that exist regarding the natural clinical progression of terminal illnesses and clinical indicators that can point to the onset of such disorders, the more secure and precise the medical initiatives that propose therapeutic restrictions will be<sup>15</sup>. Feudtner and Nathanson<sup>25</sup> note that certain consolidated statistical data may offer guidance for the establishment of certain provisions and standard procedures; however, in practice, it is not possible to foresee the prognosis of a specific patient, i.e., such a procedure is essentially intuitive. Therefore, due to the principle of uncertainty, an open and honest discussion must be held between the medical staff and those that are responsible for the patient. Palliative care has been the subject of trailblazing studies, and Cadell et al.<sup>16</sup> also note the importance of conducting interdisciplinary studies on the subject of palliative care techniques. In light of the sensitive nature of the issue, investigative studies of this type have revealed that even research ethics committees have professed deep disagreement regarding the established standard procedures.

For example, until recently, an ethical debate existed concerning the deep sedation of a patient during the terminal phases of cancer, under the pretense that the lifespan of the sedated patient would be reduced. However, in other studies that have examined existing literature<sup>67,51</sup>, it was noted that, although, theoretically speaking, high doses of analgesic drugs and sedatives may inhibit the patient's respiratory control centers, the group of patients that received higher doses survived longer than the group that did not receive such doses. These scholars feel that the study that was performed on palliative care techniques set the stage for the emergence of procedures for the administration of sedatives and analgesic drugs incrementally as required by the patient. By adopting such procedures of applying such treatments incrementally, high doses of analgesic and sedative medication may be used on patients that need them without any form of distrust emerging regarding the possible reduction of the lifespan of that patient.

Despite the ongoing communication between the medical staff and those that are responsible for terminally ill children, ethical conflicts of interest remain regarding the decision-making process. Ham<sup>34</sup> mentions the case of the parents of an English child that requested further treatment for their child, even though it went against the wishes of the medical staff. The parents wanted to try a second bone marrow transplant, which the doctors were against. The English courts decided in favor of the position of the

doctors, which considered such a procedure to be futile and obstinate.

Feltman et al.<sup>23</sup> also describe a peculiar case involving severe comorbidities - extreme prematurity and omphalocele. The parents insistently requested that the infant be subjected to a surgical procedure and, afterwards, to cardiorespiratory resuscitation techniques; however, the medical staff foresaw that such procedures would not prove effective. Such cases reveal that an ethical and legal tendency exists which favors the decision of the medical treatment staff in not implementing treatment techniques in situations where clinical conditions are unfavorable or that are contrary to medical principles. In other words, it is more acceptable to renounce certain forms of treatment than to have them suspended.

Another type of conflict arises when doctors prescribe the suspension or reduction of treatment procedures and the parents wish to have them maintained. It is understood that such a conflict of interests should not be discussed during the first meetings between the medical staff and the parents or caretakers; it should only be mentioned once this objection is voiced repeatedly. To avoid or minimize the emergence of such a situation, the proposal for restricting therapy should be introduced gradually during the mid-term planning stages as signs emerge that progressive and irreversible clinical deterioration has begun. Such a restriction should not be proposed at the last moment, in accordance with the principles of palliative care.

Notwithstanding the above, various studies<sup>13,21,27,49</sup> have attempted to establish that, within such circumstances, an ethics supervisory committee (such as an institutional ethics supervisory board) may be consulted, and, in extreme cases, a request may be forwarded to the local courts. Powell<sup>56</sup> furthermore argues that, although therapeutic restrictions have not been formally accepted, the medical staff is not ethically obligated to prescribe invasive intensive care procedures, such as the constant collection of blood samples, the monitoring of the patient with electrodes (which requires a certain immobilization of the patient), the maintenance of the patient's water balance with a catheter, and so forth.

Legal opinion regarding this issue varies from country to country. Scholars<sup>52,63</sup> have described the tendency in the US of forcing doctors to conduct routine intensive care procedures if the patient does not expressly agree with the implementation of therapeutic restrictions. Only in specific situations, which are very well supported by pre-existing standard procedures, such as terminal neoplasia or extreme prematurity<sup>69</sup>, represent an exception to this tendency. In the UK, however<sup>34,77</sup>, the overall trend has been

to uphold the decisions and standard procedures of the doctors should diverse health service staff display a consensus regarding the futility of continued therapeutic procedures.

Gunn et al.<sup>33</sup> discussed the critical situation of a patient that had a brain tumor, which would reduce his life expectancy, however, due to respiratory morbidity, the patient succumbed to a prolonged vegetative state. According to the authors, the prevailing ethical-legal stance that exists within the United States would have been more forceful than that of other countries in terms of suspending treatment even if it were against the wishes of the patient's relatives. For example, in Singapore, Japan, Germany and Russia, the moment of parental grieving and the advanced medical care procedures would be allowed to progress until the parents were comfortable with the situation. According to Schildmann et al.<sup>65</sup>, in Germany, one can find resistance to the practices of therapeutic restriction, which were used abusively during the period of Nazism, such that it is easier to not protect someone with treatment than to suspend some type of life support.

#### *Current treatments that will be suspended/renounced*

With respect to therapeutic restrictions, the first decision to be taken involves the order not to initiate cardiopulmonary resuscitation<sup>7</sup>, a procedure whose overall rate of efficiency is approximately 30%. In cases of terminally ill patients, such a patient may survive after resuscitation procedures have been initiated; however, the chances that they will be discharged from the hospital are still very slim. In other words, the acceptance of this therapeutic restriction is profoundly symbolic. The order to not resuscitate means that the patient and his family members recognize the medical diagnosis of the terminal nature of the clinical situation, and that a possible increase in the duration of their loved one's life will be brief and that no mechanisms exist for controlling the disease.

Although Feltman et al.<sup>23</sup> argue that any treatment may be evaluated with respect to its suspension or renouncement, more drastic decisions regarding ethics fall upon the procedure of artificial breathing/mechanical ventilation support and enteral nourishment, each of them presenting peculiar ethical aspects. Advanced support for mechanical ventilation through the insertion of orotracheal intubation represents a treatment method that is too invasive and painful, and frequently requires strong sedatives and analgesic medicine in order to be introduced or maintained. Notwithstanding, the suspension of mechanical ventilation methods usually causes death in a short time span, which leads to the question of

where the boundary lies between therapeutic restriction and euthanasia.

In light of the limits that have been established in this line of questioning, scholars<sup>51,60</sup> warn that, since the concept of therapeutic restriction is quite new, it becomes necessary, in addition, to create a vocabulary that can abstractly describe the nuances that are involved in the clinical situations that are experienced. In other words, practical terms must be coined that make clear the proper distinction between negligence, therapeutic restriction and euthanasia.

Geller et al.<sup>32</sup> affirmed that respiratory care presents possibilities that are less drastic and invasive than mechanical ventilation. It is possible to apply non-invasive care or even ventilatory care via a tracheostomy instead of orotracheal intubation, for example. These authors have listed therapeutic restriction opportunities with respect to respiratory care: 1) not initiate any measure in this regard; 2) not resort to orotracheal intubation; 3) restrict care procedure to tracheostomy if the patient has already been subjected to one; 4) restrict care to non-invasive procedures; or 5) initiate mechanical ventilation for a predetermined time period, at the end of which the patient shall have the tubes removed irrespective of having recovered or not.

Researchers<sup>30,32,45</sup> recognize that, clinically speaking, it is clearly futile when the organ that is being treated is failing despite the technological procedure that is being applied to it. In the case of mechanical ventilation within the context of terminal patient care, if the ventilation parameters are shown to be quite high over a long period and yet the clinical parameters denote respiratory insufficiency, then euthanasia becomes a non-issue regarding the suspension of mechanical ventilation procedures. On the contrary, therapeutic obstinacy clearly exists in maintaining the life of the patient who is on a razor's edge from which he will predictably fall, considering the indispensable invasive and painful treatment that he is undergoing.

Vose and Nelson<sup>75</sup> believe that such a situation is representative of physiological futility, but that therapeutic futility may also refer to the entire clinical diagnosis of the patient when each form of advanced care is performed habitually, yet the condition of the patient is clearly deteriorating progressively, such as with patients that have neurodegenerative disorders. Frader and Michelson<sup>27</sup> add that, in the context of terminally ill patients, if the patient must be deeply sedated in order to administer mechanical ventilation procedures, and not due to his clinical baseline condition, this is also a criterion that is an indicator of the existence of therapeutic obstinacy.

Respiratory care presents nuances in which it is not clear if only therapeutic restriction has been implemented or if the patient lost his life at that moment. Certain studies<sup>23,69,75</sup> describe the ethical prohibition of applying neuromuscular blocking agents during the removal of the patient's tubes, as obviously, if the diaphragm is paralyzed, death is brought about by the drug, not by the baseline illness. Regarding this issue, Morrison and Berkowitz<sup>50</sup>, in addressing the need to distinguish between procedures, have determined that the term "euthanasia" may be used only when lethal medication is administered during the patient's intercritical periods. In other words, euthanasia as a practice would only be conducted during moments of clinical stability (that is, when there are no signs or symptoms of the illness worsening), and even so only when the patient has clearly expressed his wish to go through with the procedure. Alternatively, within contexts of emergency, the terminology that is most properly applied is "therapeutic restriction".

Torres et al.<sup>69</sup> elucidated that the removal of the patient's tubes, within the context of palliative care, must only occur after the patient has been off muscle relaxers, receives higher doses of sedatives or has had his ventilatory parameters decreased until the moment the tubes are removed and are substituted by some other less invasive respiratory care procedure, such as nasal oxygen cannulas. However, Penner et al.<sup>54</sup>, upon studying a case of Duchenne muscular dystrophy, showed that it is not clear if mechanical ventilation within the patient's home via tracheostomy constitutes therapeutic obstinacy, or if it is simply a chronic form of care in the face of a severe and knowingly fatal disease.

In this sense, studies<sup>23,77</sup> have shown that less invasive methods, such as tracheostomy or gastrostomy, are not, upon initial analysis, obstinate, but may in and of themselves require certain safeguards and generate other complications. The complications that are associated with these procedures may be indicative of the existence of therapeutic obstinacy. Similarly, the case of the patient that was described by Leeuwenburgh-Pronk et al.<sup>43</sup> shows how the distinction between therapeutic restrictions and euthanasia can be blurred: the patient's condition had been kept stable, albeit in critical condition, merely through the use of oxygen through the nose or via a catheter, which constitutes, in other words, non-invasive treatment, the removal of which, however, brought about death in a matter of a few hours.

The neuroethical issue is particularly important within the decision-making conflict regarding the suspension of respiratory care. In accordance with many authors<sup>19,20,25,55</sup>, in dealing with patients that suffer from severe cognitive sequelae (cerebral



malformations, persistent coma, cerebral palsy, and so forth), doctors felt less discomfort in recommending the suspension and omission of treatment procedures than when dealing with non-oncological illnesses that do not affect the patient cognitively, such as neurodegenerative muscular disorders<sup>28,54,67</sup>, cystic fibrosis<sup>46</sup>, and pulmonary insufficiency due to hemosiderosis<sup>37</sup> and so forth.

However, with respect to chromosomopathies and/or cerebral malformations, other studies<sup>12,76</sup> defend the position that the diagnosis in and of itself is not sufficient to recommend the implementation of therapeutic restrictions. This refers to diseases whose clinical manifestation may present varied intensities, from mild symptoms to severe complications that generate a situation in which the patient is dependent on life support technology. With certain frequency, patients that display these symptoms undergo periods of clinical stability. Feudtner<sup>24</sup> presents an illustration of the clinical condition, as a function of time, of such patients, in which one can note that the terminal nature of the condition becomes evident: 1) after the patient has been placed in an ICU, when his overall clinical condition will not return to its previous levels (stable discharge, however with sequelae); and 2) when the patient begins to suffer from severe, recurrent clinical complications.

With respect to nutrition or hydration via nasogastric probe or gastrostomy, in accordance with some authors<sup>12,20,26</sup>, nutrition only becomes a matter of essential care if the patient can demonstrate the capacity to swallow or if he is recovering that capacity. As a result, in cases where the patient is in a constant vegetative state, medical professionals in the UK and the United States allow the patient's guardians to make the decision. In other words, doctors will not recommend the suspension of such care; however, the process of feeding the patient via probe is suspended - while doses of sedatives are increased and the medical staff await death by dehydration - should the legally responsible parties so request it.

Leeuwenburgh-Pronk et al.<sup>43</sup> state that, generally speaking, the parents request suspension of the child's nutrition because the overall clinical condition of the care is too much of a burden, even though nutritional care in and of itself does not apparently cause any discomfort to the patient. Morrison and Kang<sup>51</sup> state that feeding procedures may be suspended should they cause discomfort to the patient. Hidayat et al.<sup>35</sup> describe the case of a young girl with terminal cancer who felt very hungry and had a strong desire to eat, but suffered with involuntary vomiting that dehydrated her every time it occurred. Although such events are commonplace in the United States, according to Wellesley and Jenkins<sup>76</sup>, at

least half of American doctors do not agree that the suspension of artificial nutrition procedures is an ethically acceptable form of therapeutic restriction. Devictor and Latour<sup>19</sup> have shown that, in European countries, a tendency may exist to not initiate artificial nutrition procedures in specific cases, should the patient's guardians agree; however, the suspension of such procedures is rarely recommended.

Lastly, scholars<sup>26,75</sup> emphasize that, with respect to the financial cost of treating terminal patients, it is not possible to affirm that the money that was not spent on a certain patient will necessarily be allocated to another patient that requires some form of treatment. Health care costs are monolithic; such that particular cases do not generate a significant financial impact on the system.

### Final considerations

The therapeutic decision to initiate treatment or not, based on its double effect, is a debate that merges technical aspects with ethical issues, and should take into consideration the value of the patient's dignity as a human being. No treatment in and of itself is futile; the futility can be attributed to the relative value of that treatment, which is linked to the circumstances surrounding that type of treatment and the overall clinical context. In other words, the underlying issue is whether the possibility of a cure exists, or if the treatment is administered simply to provide relief to the patient<sup>6</sup>. As such, the implementation of therapeutic restrictions is not a decision that should be made solely by a single health care professional, but by the entire team, for which the director is merely a spokesperson, in light of the fact that the legal responsibility that is involved is, above all else, institutional. Children that suffer from severe cerebral malformations most commonly suffer from terminal complications that are related to the respiratory apparatuses that they depend on, so that the most heated bioethical debate relates to not prescribing the use or suppression of mechanical ventilation.

Although therapeutic obstinacy is considered by society to be ethically questionable, current Brazilian law does not reflect this outlook. Laws exist that aim to restrict negligence, recklessness and euthanasia; however, no formal regulation or law exists to contravene excesses or the over medication of the terminally ill patient<sup>7</sup>. Notwithstanding, CFM Resolution 1.995/2012<sup>80</sup>, which concerns provisions regarding life expectancy, attempts to establish ethical-legal regulations that are extremely similar to those found in American culture, which are based on agreements and written decisions. This seems

relatively strange to European culture, and perhaps also to that of Brazilians, both of which tend to adopt the stance of non-objection instead of favoring an agreement that was proposed by the patient himself.

From the ethical-legal point of view, currently, in Brazil, only medical staff have the authorization, in terms of palliative care, to restrict the use of diagnostic and therapeutic procedures. However, no judicial precedent exists that punishes the implementation of procedures that are characteristic of therapeutic obstinacy. To the contrary, acts of therapeutic obstinacy may be erroneously treated as the *maintenance of the patient's right to live*, in accordance with the Public Prosecutor's Office's dispute<sup>81</sup> against CFM Resolution 1.805/2006<sup>82</sup>. In conclusion, patients that

suffer from severe cerebral malformations are terminally ill, and are prescribed palliative care, which gives rise to the main ethical dilemma of whether or not to limit the patient's respiratory support. The decision of whether or not to limit certain efforts must be taken by the health care institution, by its medical staff, and the dialogue with the patient's parents or guardians represents one of the main ethical pillars that must be addressed in such situations. Most certainly, the indiscriminate use of advanced technology for patients in whichever clinical state is no longer ethically acceptable. Currently, the medical community is left to face the reality at hand and refine its practices in order to properly restrict the therapeutic procedures that terminal patients are subjected to.

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#### Participation of the Authors

This work is part of the doctorate thesis of Dario Palhares, overseen by Antônio Carlos Rodrigues da Cunha. Íris Almeida dos Santos contributed to the bibliographic survey and the preparation of the discussion and final considerations.

