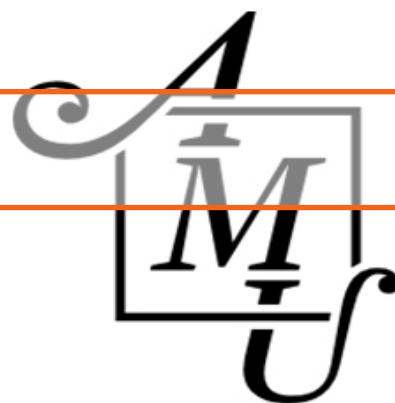


6. Revisión 4



Decision-making in end-of-life care in pediatrics: ethical controversies and management of situations in clinical practice

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Abstract: The concept of "Limitation of the therapeutic effort" (LTE) is based on the withdrawal or non-initiation of futile treatments that delay the death of the patient and prolong their agony. Although medical advances have made it possible to reduce infant mortality rates, management of end-of-life decisions at these ages continues to be difficult and includes ethical and controversial issues of complex resolution. This paper reviews the medical literature and various reference guides aiming 1)

to describe some of the most frequent ethical controversies described in the literature and 2) to offer guidance on how to deal with situations of uncertainty that can present themselves in the clinic, integrating them into the physician-family-patient relationship. To do this, the body of the review has been divided into several sections: first, we will review the most recent bibliography related to the complexity and types of LTE described, and the ethical controversies that this poses. Next, we will address the role of the doctor in LTE and the interaction between these ethical controversies and the doctor's own morals, where an attempt will be made to establish a general orientation of the steps that the doctor should take when making decisions. The next step goes beyond the purely care setting and will consist of including the doctor in the decision-making process relating to the family, going through the bibliography that tells us about the most frequent needs and problems that can arise in this context. Finally, we will integrate the pediatric patient in this process, analyzing very briefly the most frequent problems that may occur in the last moments of life. All this makes us consider the importance of clinical practice guidelines in LTE.

Keywords: withdrawal, withholding,

limitation of therapeutic effort, pediatrics, end of life care.

Introduction

The 2/2010, of April 8 law "of rights and guarantees of the dignity of the person in the process of death," defines the Limitation of Therapeutic Effort as the "withdrawal or non-establishment of a life support measure or of any other intervention that, given the poor prognosis of the person in terms of future quantity and quality of life, constitutes, in the opinion of the health professionals involved, something futile, that only contributes to prolong in time a clinical situation lacking in reasonable expectations for improvement" (1). This implies LTE should be considered as a clinical practice that tries to avoid "therapeutic obstinacy" (article 21). The debate about the limitation of therapeutic effort is increasingly present, due to the appearance of new advances in various medical fields that make us ask the question of whether everything technically possible is ethically acceptable.

In spite of the difficulty involved in the decision making process, there is a general model proposed by the Public Health System of Andalusia (2), which includes, among other aspects, the initial evaluation of the patient by professionals of the Medicine and Nursing who take care of them, collective deliberation within the framework of clinical sessions, communication of the information to the patient (family or representative) and consulting the Ethics Committee in case of discrepancies between professionals or conflict with the patient (family or representative).

In this sense, LTE in pediatric patients presents a series of particularities (2): the patient is underage, so that the decision making is carried out within a special context (on numerous occasions, and bearing in mind how mature the child is, it is the family or whoever has parental authority that must act, according to the principle of beneficence for the child); the functional capacity for the recovery of the patients of pediatric age is greater than that present at other age groups, so that the decision making before other-

wise apparently very unfavorable processes can be enormously complex, making it difficult to establish the indication of LTE. Therefore, it is essential to have an integrated decision-making model, in which the health team, family members and legal guardians, and even the pediatric patient himself participate actively according to their degree of maturity and the factors one must bear in mind to assess the mental capacity of the child: understanding information and retaining it, using it in a logical manner, etc. (3).

The goal of the present work is to describe, through bibliographic review, the most recent interventions of controversy related to the limitation of the therapeutic effort in the area of pediatrics at a clinical and ethical level, besides trying to offer different forms of action for conflict resolution. To this end, we will try to address the issue in a holistic way, paying special attention to the interrelation and need of communication between healthcare personnel and families of pediatric patients.

Material and methods

A review of the biomedical literature available on Medline was carried out through the PubMed search engine, using as key terms "life-sustaining treatment", "children", "withholding" and "withdrawal" related by the Boolean operator " AND "and establishing as filter" 10 years ", in order to visualize all the articles related to the subject published in the last ten years. A total of 31 articles were obtained, of which 13 were selected, taking into account the title and summary of them, using as an inclusion criterion the adequacy to the topic that is intended to be studied. Bibliography related to those articles were also selected, using a cluster search. In addition, the guidelines "End of life in childhood and adolescence: ethical and legal aspects of health care" (2011) and "Limitation of therapeutic effort in Intensive Care: Recommendations for the elaboration of protocols" (2014), of the Andalusian Regional Ministry of Health, and the "Practical Guide for the Management of Palliative Care Neonatal Units" (First Edition, February 2014) of the Royal College of Pediatrics and Child Health in collaboration with the NHS Foundation Trust were used as

consultation guides.

Forms of LTE in pediatrics

As in the adult patient, we can distinguish two fundamental types of LTE in pediatrics: withholding (not initiating certain therapeutic interventions) or withdrawal (removing previously initiated interventions). Although there is no ethical difference between the two modalities, in practice it is more difficult to accept withdrawal measures: in some studies (4) there are differences in the healthcare personnel (doctors and nurses) in their positioning. In relation to the withdrawal or establishment of ventilatory support, being much more conflicting the withdrawal of these interventions. It is striking, however, that in countries such as the United Kingdom, withdrawal rates are well above average (5). Among other explanations to this fact, we could find that the legal and ethical framework is more clearly defined in the United Kingdom than in other countries (General Medical Council, Royal College of Paediatrics and ChildHealth).

The causes of infant death and, therefore, the analysis of possible situations of LTE application in Pediatric Intensive Care Units (PICUs) have been modified over the last years (6). The decrease in the number of deaths related to neural tube defects is due to the increase in the procedures for early diagnosis and folate supplementation in the periconceptional period, as well as improvements in postnatal survival in these pathologies. In contrast, certain congenital diseases and serious infections with irreversible sequels (severe neurological damage, for example) are some of the common causes of death in pediatric patients (5).

Palomeque and his colleagues carried out a retrospective study in 2011 in relation to LTE at a PICU in Barcelona (7). 97 deaths of the 311 registered in the Unit occurred in the LTE context. Among them, the most frequent diagnosis was related to respiratory failure, followed by cardiopulmonary arrest and sepsis. In addition, as concomitant pathologies, neurological involvement, neoplasia, congenital heart disease and neuromuscular disease were highlighted. The most used procedure was the withdrawal of ven-

tilation or oxygen therapy. Also worth highlighting were the removal of inotropes and antibiotics. Paediatric patients with neurological diseases and very severe cognitive sequels were the main groups in which it was decided to apply LTE.

It is important to point out some special types of LTE in pediatrics, such as withdrawal of nutrition and artificial hydration. Hellman and Williams (8) argue that, despite the low frequency of withdrawal of artificial nutrition and hydration a few years ago, it is currently included within the spectrum of LTE. We can ask ourselves the question of whether this is a medical therapeutic procedure or if on the contrary, it represents a form of essential care to which every person is entitled. The authors argue that invasive procedures involving many types of artificial nutrition (nasogastric tubes, intravenous accesses, etc.) can carry risks that aggravate the situation and prolong the suffering of the patient, considering their advantages and disadvantages as medical treatment. In addition, there is no evidence that artificial nutrition improves the patient's quality of life. In fact, withdrawal of hydration decreases nausea, vomiting, and diarrhea, and if done, should be done in conjunction with nutrition, as exclusive nutrition prolongs agony without achieving the reduction of symptoms that causes the withdrawal of hydration.

However, in a study carried out by Hubert (9) in which the opinion of physicians of the PICU of 24 French hospitals was collected, only 18% of the doctors considered the withdrawal of nutrition and hydration as acceptable, while 31% considered it totally inconceivable in any situation (more than 80% of these doctors did accept other measures of LTE, such as those related to ventilation, hemodynamics or dialysis).

In neonatology, on the contrary, the field of LTE has been well studied and there is a broad consensus, although each situation must be analyzed individually (10). Generally, resuscitative treatment is not initiated in premature infants with gestational ages of 23 weeks and/or weighing not less than 400 grams (except in cases of extreme vitality or retarded intrauterine growth),

anencephaly, trisomy 13 or 18 Confirmed and fetuses with signs of death (absence of breathing and beat, maceration). If resuscitation has already been initiated, it will be discontinued upon confirmation of an incurable disease (eg, anencephaly) or if there is no response after 10 minutes of cardiopulmonary resuscitation (Table 1).

The role of the doctor in the LTE's processes

The Code of Ethics of the General Council of Official Colleges of Physicians (11) establishes in Chapter VII the form that the physician should act at the end of the life of any patient. Article 36 refers that "the physician has a duty to try to cure or improve the patient whenever possible. When it is no longer possible, it remains the obligation to apply the appropriate measures to achieve its well-being, even if this could lead to a shortening of life "and "the physician should not undertake or continue diagnostic or therapeutic actions without hope of benefits for the sick, when they are taken in a useless or stubborn fashion. It must take into account the explicit will of the patient to refuse such treatment to prolong his life. When his state does not allow him to make decisions, he will take into consideration and value the indications previously made and the opinion of the related responsible people. "

In this way, the importance of the doctor-patient relationship (and relatives, which in the context of LTE in Pediatrics acquires a key dimension, as we saw above) and the need to continue providing psychological, material and technical support to the patient, without obstinacy, in the final moments of his life, because the function of the doctor does not end when the options of cure are not present. We will see the distinctive features of these matters in the following sections.

Frome and colleagues (12) conducted a survey to pediatric intensivists in order to determine the influence of personal beliefs and preferences (in relation to maintaining life support for themselves in hypothetical pathological situations) when recommending LTE to family members

from the patients. The results were statistically significant, so that, for example, physicians who had less preference for maintaining life support under certain conditions recommended not intubating their pediatric patients and vice versa.

The variability of opinions among medical professionals and the impact of personal preferences make it necessary to establish protocols of action in the most objective way possible. In this sense, the Regional Ministry of Health, through the guide "Limitation of Therapeutic Effort in Intensive Care: Recommendations for the elaboration of protocols" (2), calls for the obligation of each unit to establish its own protocols for LTE and its adequacy to the contents exposed in that document. The need to make decisions according to protocols and in teams is essential in LTE in pediatrics (Table 2).

In addition, the medical team should be in close contact with the corresponding Ethics Committee, since many doctors report that each clinical situation is unique and many situations are so complex that the guides do not contemplate their peculiarities (13).

The parents before the LTE: key features in the relationship and medical communication with the family.

The needs of pediatric patients and their families are complex and should be considered with its own special features in contrast to LTE in adult patients (14). Adults can verbalize their intentions and make a consensual decision with the doctor (or their relatives do, in the case of patient incapacity, who, however, could have expressed their point of view when they were able). However, decision making in the child comes conditioned to cognitive and emotional development, which often makes parents responsible. This means the parents have to face especially complicated and painful situations. Therefore, the attention of the professionals towards the relatives of the pediatric patients becomes a more relevant aspect that in any other type of patient. The Royal College of Pediatrics and Childs Health proposes psychological-emotional and religious-spiritual (belief-based) support for patients' rel-

atives (15): most UK hospitals have a specific multi-faith team that provides religious support to family members. In addition, it is important for health personnel to respect these religious beliefs and rituals. As for psychological support, it is imperative when parents have to make critical decisions and it is necessary to help them cope with the affliction linked to the process of illness and death. Mayer and Longden (16) argue that giving parents the possibility that end-of-life care of pediatric patients to be carried out in the family home can have positive effects in these circumstances.

In contrast, although it is always intended to avoid conflicts through dialogue and consensus, it is often the case and disagreements may arise. Conflicts between parents and physicians occur with a high frequency (17). Jenkins and Wellesley (18) refer to an expectation gap that appears in many parents to the great confidence that they have in modern medicine and their inability to accept the absence of effective therapeutic measures to solve the illnesses of their children.

The opposite may also be the case: some parents propose establishing LTE measures before any member of the healthcare team considers it appropriate or opposing the health care professional's opinion. In these circumstances, the mediation of the Ethics Committees could be requested, although on extreme cases if the decision of the parents or the doctors is not objectively in relation to what is best for the child, a judicial process may be initiated. In cases where the prognosis and the measures to be implemented are not sufficiently clear, the medical team should shift towards the decisions made by the family, provided that it does not imply carrying out counterindicated actions (2).

Palliative and pediatric care at the end of life

Some experts consider the term "Limitation of Therapeutic Effort" to be inappropriate and suggest replacing it with "adjustment," which implies adaptation to the patient's needs rather than "failure to do" (19). Therefore, "LTE" should not be equivalent to "abandonment", the duties of the healthcare team and the integral care to

the patient must remain until the end of life.

There are many symptoms that patients can suffer depending on the pathology they present. Here, we refer to the clustering of symptoms and their proposed treatment at the Durban World Congress (20) in relation to the withdrawal of mechanical ventilation (one of the most frequent forms of LTE and symptom management similar to other types of LTE). The most important are pain and anxiety, dyspnea, nausea, and vomiting. In a study conducted in three pediatric hospitals (21), Meyer, Burns, Griffith, and Truog identified that when it came to decision making, the most influential factor for parents was the perception of pain in their child, along with the quality of life and likelihood of improvement. It is also important to bear in mind that the use of analgesics is especially troublesome in pediatric patients (15): tools to measure pain, on many occasions, have many limitations and its adequate determination can be problematic. Also, the use of oral versus intramuscular or subcutaneous (when possible) analgesics is preferred. The process of palliative sedation in pediatric patients is not well defined (2) and must be carried out according to clinical indications, always recording the procedures in the Clinical History and upon request of informed consent.

It is necessary to say that, sometimes, the information process related to LTE not only includes the family, but also the pediatric patient himself, who, depending on their ability to decide, their degree of maturity and understanding, may enter the deliberative process of LTE (3). In order to talk about illness and death with pediatric patients, we must also adapt information to the characteristics described above, develop communication skills such as active listening, nonverbal communication, trust transmission, seeking naturalness and emotional closeness.

Conclusions

The conflicts and ethical controversies that arise when there are procedures to limit therapeutic effort in pediatrics need the elaboration of specific protocols of action, reference guides, and recommendations, in order to obtain objective guidelines that guide the way of acting in complicated

situations. Equally important is the understanding and interrelation between health personnel, who must also be in close contact with the Ethics Committees.

The concept of "limitation" should not be understood as "abandonment": the care of the doctor continues and is, even more important, in those situations in which healing is not possible. The family constitutes a basic pillar in any type of procedure related to LTE and the necessary understanding of the health personnel with it, as well as its particular point of view in relation to several aspects that traditionally were only the competence of the medical field, issues to which are increasingly given more relevance in the literature.

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Tabla1. Consideraciones en reanimación neonatal	
No inicio de reanimación	Interrupción de reanimación
<ul style="list-style-type: none"> - Edad gestacional \leq 23semanas y/o peso \leq 400 g (salvo vitalidad extrema o crecimiento intrauterinoretardado) - Anencefalia - Trisomía 13 ó 18 - Signos de muerte: ausencia de respiración y latido, maceración 	<ul style="list-style-type: none"> - Confirmación de enfermedad incurable (por ejemplo, anencefalia) - Ausencia de respuesta tras diez minutos de reanimación cardiopulmonar

Fuente: elaborado a partir de los datos de Iriondo M, Burón E, Thió M et al. (Referencia bibliográfica 10)

Tabla 2. Orientaciones sobre el registro del proceso LET en la historia clínica
<ol style="list-style-type: none"> 1. Previo a la LET: evaluación de la capacidad de decisión, valoración integral del paciente, exploración de las preferencias del paciente/familia/representante. 2. Propuesta de LET en relación al diagnóstico y pronóstico, identificando a las unidades y profesionales que participan en dicha propuesta. 3. Sesión clínica: deliberación colectiva de la propuesta, quedando registrada la presentación del caso, deliberaciones, decisiones y otras circunstancias (actuaciones complementarias, objeciones de conciencia). 4. Proceso de comunicación con el paciente/representante/familia. 5. Realización de LET: tipo de medidas, momento, profesional que las realiza y resultado del procedimiento. 6. Consulta al Comité de Ética Asistencial en caso de discrepancias entre profesionales o conflicto con el paciente/familia.

Fuente: modificado de "Limitación del esfuerzo terapéutico en cuidados intensivos: Recomendaciones para la elaboración de protocolos" Consejería de Igualdad, Salud y Políticas Sociales. Junta de Andalucía (2014).

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