

End-of-life care in children: the Brazilian and the international perspectives

Patrícia M. Lago,¹ Denis Devictor,² Jefferson P. Piva,³ Jean Bergounioux⁴

Abstract

Objective: To analyze the medical practices and the end-of-life care provided to children admitted to pediatric intensive care units in different parts of the globe.

Sources: Articles on end-of-life care published during the last 20 years were selected from the PubMed, MEDLINE and LILACS databases, with emphasis on studies of death in pediatric intensive care units in Brazil, Latin America, Europe and North America, using the following keywords: death, bioethics, pediatric intensive care, cardiopulmonary resuscitation and life support limitation.

Summary of the findings: Publications on life support limitation (LSL) are concentrated in North America and Europe. In North American pediatric intensive care units there is a greater incidence of LSL (~ 60%) than in Europe or Latin America (30-40%). These differences appear to be related to cultural, religious, legal and economic factors. Over the last decade, LSL in Brazilian pediatric intensive care units has increased from 6 to 40%, with do not resuscitate orders as the most common method. Also of note is the low level of family participation in the decision-making process. A recent resolution adopted by the Federal Medical Council (Conselho Federal de Medicina) regulated LSL in our country, demystifying a certain apprehension of a legal nature. The authors present a proposal for a protocol to be followed in these cases.

Conclusions: The adoption of LSL with children in the final phases of irreversible diseases has ethical, moral and legal support. In Brazil, these measures are still being adopted in a timid manner, demanding a change in behavior, especially in the involvement of families in the decision-making process.

J Pediatr (Rio J). 2007;83(2 Suppl):S109-116. Death, limitation of life support, pediatric intensive care, medical ethics.

Introduction

The second half of the twentieth century saw enormous medical advances, resulting in an increase in life expectancy, but also bringing new ethical, moral and economic issues, in consequence of exaggerated use of technological resources with terminal patients.¹

The technological advances in medicine have made it possible to save the lives of critically ill patients as long as there is some chance of reversibility. Nevertheless, for those patients with no possibility of recovery, the use of curative measures, in addition to being expensive with no benefit, end up causing only pain and suffering. In such cases, by prolonging life, medical technology makes the process of

1. Pediatra intensivista, Hospital de Clínicas de Porto Alegre (HCPA), Porto Alegre, RS, Brasil. Doutora, Faculdade de Medicina, Pontifícia Universidade Católica do Rio Grande do Sul (PUCRS), Porto Alegre, RS, Brasil.
2. Chefe, UTI Pediátrica, Hospital Le Kremlin Bicêtre, Paris, França. Membro, Departamento de Pesquisa em Ética, Hospital Le Kremlin Bicêtre, Paris, França.
3. Professor adjunto, Departamentos de Pediatria, Pontifícia Universidade Católica do Rio Grande do Sul (PUCRS) e Universidade Federal do Rio Grande do Sul (UFRGS), Porto Alegre, RS, Brasil. Chefe associado, UTI Pediátrica, Hospital São Lucas, PUCRS, Porto Alegre, RS, Brasil.
4. Pediatra intensivista e membro, Unidade de Hematologia, Hospital Le Kremlin Bicêtre, Paris, França. Membro, Departamento de Pesquisa em Ética, Hospital Le Kremlin Bicêtre, Paris, França.

Suggested citation: Lago PM, Devictor D, Piva JP, Bergounioux J. End-of-life care in children: the Brazilian and the international perspectives. *J Pediatr (Rio J)*. 2007;83(2 Suppl):S109-116.

doi 10.2223/JPED.1627

dying slow and painful. The major challenge is to define which patients will benefit from full technological support. In other words, to distinguish between those whose conditions are potentially curable, from those for whom, due to the irreversibility of their course, therapeutic measures are useless, classifiable as futile.²

This identification of irreversibility is particularly difficult with children. Since pediatric intensive care unit (PICU) mortality rates oscillates between 5 and 15%, there is every expectation that the great majority of children admitted will be cured. Therefore, the dominant attitude within the medical team, irrespective of the severity of the case, is to adopt measures aimed at saving life. To determine terminal status in these situations requires a certain amount of time, to establish with absolute confidence that a child is in an irrecoverable situation.³

In intensive care units (ICU), the moment of death, in many cases, is determined by the decision to limit the support that is keeping the patient alive. Life support limitation (LSL) can be defined as the process by which the physician either does not provide or withdraws treatments that will not alter the final outcome, but are just prolonging the process of death.⁴⁻⁶

The worldwide incidence of LSL is variable and multifactor, and has exhibited a dramatic increase over the last 15 years.⁷ Several different studies have demonstrated that, currently, more patients in ICU die from LSL than after a failed cardiopulmonary resuscitation (CPR). Among adults, the incidence of LSL varies from 40 to 90%, with the frequency in PICUs being lower.^{7,8}

Life support limitation in pediatric practice

It is estimated that approximately 6 million children die every year worldwide, and many of these will die in a PICU. In Western culture, the death of children results in an extremely painful process of mourning. It is, however, intriguing that this is very little studied or discussed by a large portion of intensive care pediatricians.⁹

At least two interlinked factors contribute to the fact that research publications into death in PICUs should be so few in number: the low mortality in PICUs (around 10%) and the high expectation of a cure. The large potential for cure means that the medical team and the family will only concern themselves with the quality of death once all possibilities for recovery have run out.¹⁰ It could, therefore, be stated that definition of irreversibility in children is a more complex process and one which demands more time.

The maxim that a child "is not just a small adult" is not only applicable to pharmacology or medical pathophysiology; it is also true with relation to end-of-life care. Children's relationships with their families and their psychological and

spiritual requirements differ from those of adults, and this has an influence at the moment of death.¹⁰

Pediatric end-of-life practices are aimed to meet the best interests of the child and their family. However, in a majority of cases, the patient does not have the capacity to participate in the decision-making process. Medical practices during the moments preceding the death of a child include defining irreversibility, communication and discussion on treatment plans, shared decision-making, support for the family and, definition of palliative care, including analgesia and sedation.^{1,10}

The first studies of LSL in children were carried out with very low birth weight infants. It was only at the beginning of the 1990s that the first studies into end of life in PICUs were published in the USA,^{5,11} reporting that more than 30% of deaths were preceded by some form of LSL.

This concern with defining the limits of investment in pediatric patients has become ever greater worldwide during the last decade. Currently, the incidence of LSL in PICUs varies from 30 to 80%, depending on the region assessed.^{1,8,12,13}

Variations between countries in life support limitation

There are significant differences between countries in terms of intensive care unit end-of-life practices. These differences have been well documented in international retrospective and prospective studies involving adults children and newborn infants.¹⁴⁻¹⁹

Differences between countries

Several different studies¹⁴⁻¹⁹ have demonstrated marked differences not just between different regions on the planet, but also within each country, even in the same city.^{20,21} These differences exist in all phases of the LSL decision: from the initial process to its conclusions, ending with the withdrawal or withholding of life support treatment.

With relation to decision making, the principal difference between countries is in the degree of involvement of the patient and/or their family in the decision-making process. The question of who should be responsible for this decision-making is difficult to answer. In a PICU the patient is incapable of participating in the decision, and the degree of participation of the family, the medical team and the legal system in this process is highly variable around the world.^{17,20}

The American Academy of Pediatrics has published guidelines on this theme, defining the responsibility for taking this decision for the child as lying with the family.²²⁻²⁴ This attitude is fundamentally based on the concept of autonomy, which is an important principle of medical ethics and one of the pillars of United States society.²⁵ Some studies

have shown that this directive is not followed in Europe.²⁶ one of these studies demonstrated that in France it is the doctors that take the leading role in decision-making. The argument for this practice is based on the fact that French doctors believe that the parents of children who are in PICUs had a compromised decision making capacity because of the stress they are under. In this case the doctors prefer to protect parents from a feeling of guilt resulting from taking a decision at the inevitable end of the life of their child.²⁶ of course, this paternalistic attitude, which does not consider the principle of autonomy, is contested by intensive care specialists from the United States.

Differences between countries also appear at the point of taking the final decision before death. The incidence of LSL is highly variable. In the USA, the first study into LSL in PICUs demonstrated that life support was limited in 32% of 300 children who died,⁵ although this incidence has increased greatly during the last decade, reaching 60% in some services.^{1,27} In Europe, withdrawal of life support is more common in northern countries (47%) than in southern ones, and families also have greater participation in decision-making process in the North.¹⁷

In Israel, LSL is rare and, when it does occur is limited to withholding support, since withdrawal is not permitted by the religion. In India, support limitation practices vary from 20 to 50% in private hospitals, however, in ICUs in deprived areas and poorer cities, LSL practices are completely unacceptable.^{2,28}

This large inequality between countries can be explained by cultural and religious differences that influence medical practices in different regions, but also by features specific to each medical team, including their academic training and the characteristics of the institution where they work, in addition to economic factors.^{20,28}

The way in which end-of-life decisions are taken also varies from one ICU to another. One study in the United States showed that, after the helpdesk and decision, withdrawal of support immediately applied. The interval between decision and action taken is 30 minutes, which is much lower than interval described in European countries, which is 2 days.^{17,18,20} The reason for this may be the way in which the decision is taken. In the USA, when a decision is taken to suspend treatment, the doctors immediately take this action in the presence of the family. In contrast, in a European ICU, the decision is essentially taken by the medical team, and so time is needed to communicate and discuss with the family and prepare them.

Reasons for the different end-of-life practices in different countries

Despite being easily identifiable, the differences in end-of-life practices between different countries are hard to

explain. Cultural and religious philosophical and legal diversity in addition to the attitudes of health professionals themselves may all be involved.

Cultural influences

In the USA and Canada, medical practices are founded on the autonomy of the patient or their family, and this is profoundly rooted in their culture.²⁵ A North American patient has the undeniable right to refuse life extending treatments, and it is the physician's duty to respect this wish. As mentioned earlier, certain studies have demonstrated that the European medical attitude is different. French doctors, for example, play the leading role in decision-making at the end of the lives of their patients, which is an attitude that is frequently interpreted as paternalistic.^{29,30}

Every patient should have the capacity of self determination, including the right to refuse when treatment is considered futile and undesirable. Recently, laws related to patient rights were adopted in France and Belgium, making explicit the duty of doctors to respect the right of competence patients to refuse care, even when their families wish treatment to be continued.^{6,7} these laws apply to autonomous patients, primarily adult patients with their decision making capacity intact. There is no reference made to specific situations for neonates or children and their families when in pediatric or neonatal ICUs.

Cultural influences have also been assessed in neonatal ICUs.¹⁶ research carried out with neonatal intensive care specialists found that the frequency with which ventilatory support was withdrawn was greater in Holland, the United Kingdom and Switzerland, intermediate in France and Germany and lower in Spain and Italy. Only in Holland and France did a substantial number of doctors admit to administering drugs in terminal cases with the objective of hastening the death of the patient. The doctors who most agreed with the idea of maintaining life at whatever price were those in Hungary, Estonia, Lithuania and Italy. Those who most considered quality of life as a priority for decision-making were from the United Kingdom, Holland and Switzerland.

Ethnic influences

Undoubtedly, culture is not static, and, even in well defined ethnic groups there may be significant differences depending on country of residence, sex, age, education, social circumstances, generation and assimilation of a host country's culture.^{5,18} Stereotypes and generalizations are almost always wrong. For example, significant differences can be observed in the style of end-of-life decisions between Japanese living in Japan, Japanese living in California but speaking only Japanese ("partially westernized Japanese") and Japanese who speak English ("westernized Japanese"). It is interesting to note that the degree of assimilation into the

western culture (here measured by the fact of using English as the dominant language) influence the type of decision taken.

Religious influence

The physician's religious background also has an influence on end-of-life decision-making. Research has been carried out in Europe demonstrating that Catholic doctors, in contrast to Protestant and agnostic ones, find the most difficulty with withdrawing or withholding treatment at the end of life.¹⁵ However, it is extremely difficult to separate religious background from other influences. In regions where the religion is Islam, LSL practices are not permitted. Similarly, the Jewish religion does not permit the withdrawal of life support.

LSL in South America

There have been few studies in South America with strong methodology that have studied LSL practices in PICUs. Medicine in South American countries is characterized by a strong paternalistic component, as in the South of Europe. Associated with this is the traditional concept that life must be maintained at whatever price, which still remains rooted in civil society and medical practice in these countries. There is no tradition of finally winning valuing patient autonomy, and end-of-life decisions end up being taken by the medical team based on the concept of beneficence and influenced by the cultural and moral values of each team of health professionals.

An Argentine study published in 2003,³¹ evaluated the mode of death of children in the PICUs of 16 hospitals and demonstrated that 65% of the patients were given full CPR before death and that the form of LSL most frequently used was the do not resuscitate order. In that study attention is drawn to the fact that, even after a diagnosis of brain death, many of these patients continued to receive full care and therapeutic intervention aimed at maintaining respiratory and cardiocirculatory functions. Furthermore, the family participated in the decision-making process in just 5% of cases.

In Brazil, three studies are very similar to the Argentine one evaluated the mode of death of children in PICUs. Kipper published research involving three PICUs in the South region of Brazil, with a 10 year interval, and demonstrated a significant increase in LSL (from six to 30%) between 1988 and 1998.²⁰ In 2005, Lago et al.³² and Tonelli et al.,³³ in simultaneous studies, described an increase in the adoption of LSL in PICUs in the South and Southeast regions of Brazil. These three studies demonstrated that the increase in LSL practices has basically been the result of do not resuscitate orders. In other words, a large proportion of children who

have died in these PICUs have continued to receive full life support (even when considered futile) until cardiorespiratory arrest occurs.

In 2003, Moritz published a study of adults in ICUs in Brazil, assessing the incidence of LSL preceding the deaths of 155 patients and found 32% of limitation practices. In that research, in addition to do not resuscitate orders also being the most common conduct, ventilatory support was not withdrawn in any cases, with only reduction or suspension of inotropic drugs being observed.³⁴

In all of the studies on death in Brazil and South America the lack of medical commitments to end-of-life care is evident. Despite the increase in LSL practices during the period preceding death, do not resuscitate orders are still the most common mode of death. The majority of studies attempts to justify this preference, when compared with northern hemisphere countries, as being related to cultural characteristics of the region. However, it is difficult to quantify what extent this is a reflection of religious cultural and legal traditions of South American countries as to what extent it is the consequence of a lack of medical knowledge on end-of-life care, associated with a low level of interest in offering the patient and their family a more dignified death. Continuation of treatment considered futile can be, depending on the situation, considered medical malpractice.⁹

The creation of end-of-life care protocols

Western countries have developed specific end-of-life care protocols. The protocols developed in the USA are different from those published in Europe. It has been demonstrated that French intensive care specialists do not apply United States recommendations with respect to LSL decisions.^{35,36} North American physicians insist on the participation of the patient or their family in end-of-life practices, whereas French doctors believe that it is they themselves who should decide what is best for the patient.^{26,30} In many Western countries, legal authorities have recognized end-of-life care as a public health problem.

The great variability in LSL practices between different countries raises questions on the globalization of bioethics. Even if it were desirable, it appears to us impractical and disconnected from reality to develop universal standards and protocols to guide in end-of-life practice dilemmas which could be applied in all locations. It should be recognized that pluralism, the local culture basis, interactions and practices between patients and professionals can result in different solutions to the same. Rather than defining the recipe of how and what to do, it is necessary to know what we are looking for, i.e., avoid patients with irreversible diseases and no chance of cure being subjected to treatments that only prolong their agony.

Medical attitudes are not always compatible with the desires of patients and their families, despite wide ranging discussions of the theme and the publications of recommendations all over the world. It is of fundamental importance that each service creates its own protocols based on global experience, and also on the context and characteristics peculiar to each institution.

It is important to point out that convergence of protocols can only involve developed western countries which have available the same treatments and advanced technology for intensive care.

Standardization of end-of-life practices

A consensus appears to be developing on what constitutes good end-of-life practices between professionals in Europe and North and South America. Standardization of end-of-life practices in PICUs implies the adoption of a series of measures and procedures which could generate confusion and anxiety for all those involved (doctors, families, medical team etc.). These are complex decisions which involve cultural conflicts, emotional trauma, the questioning of personal values and, even, concerns of a legal nature. This is exactly why every definition or major should be described in an objective manner, in great detail and in as transparent a way as possible, with discussion continuing until consensus is achieved. Therefore, when opting for LSL majors with a patient in an irreversible state, the objective is that these measures meet their requirements (to avoid suffering and futile measures), and also the ethical and moral demands of all those involved (family members, medical and nursing team. To this end, definitions must be made and consensus arrived at on irreversibility, futile measures and palliative measures.

Detailed descriptions of these definitions and practices on medical records are both an ethical and legal imperative, but, above all, they permit a full understanding by all those involved cleaner.

Doubts of a legal nature

In the Brazilian medical scenario, LSL generated a certain reluctance of a legal nature, which has now become unjustifiable with the publication of a resolution by the Federal Medical Council (Conselho Federal de Medicina).³⁷ In the considerations of this resolution, it is pointed out that it fulfills the first article, subsection III, of the Federal Constitution ("to defend the principle of the dignity of the human being as one of the fundamental principles of the Federative Republic of Brazil") and the 5th article, subsection III ("nobody shall be subjected to torture nor to inhuman or degrading treatment"). Additionally, the resolution states that it is the physician's responsibility to diagnose the patient

as suffering from an illness in the terminal phase. Based on these assumptions, it defines that:

Art. 1 The doctor is permitted to limit or withdraw procedures and treatments that prolong the life of patients in the terminal phase of a severe and incurable illness, respecting the wishes of that person or their legal representative.

§ 1 The doctor is obliged to explain to the patients or their legal representative the therapeutic modalities appropriate in each situation;

§ 2 The decision referred to in the main body must be explained and recorded in the medical record;

§ 3 The patient or their legal representative has the right to request a second medical opinion;

Art. 2 The patient will continue to receive all necessary care to alleviate symptoms that cause suffering, and is assured of integral care, and physical, psychological, social and spiritual comfort, including the right to hospital discharge.

Art. 3 This resolution comes into force on the day it is published, revoking any contrary provisions.

End-of-life care protocols

Once possible doubts of a legal nature have been ruled out and faced with a patient in the terminal phase of a disease, there are no further reasons for delaying discussion and implementation of LSL measures. Each person involved in the decision making process should be encouraged to participate respecting each other point of view (the values of the patient and their family, the medical team and the nursing team. The need to maintain the process both open and accessible appears to be central to the issue.

The patient's and their family's participation in decision-making process is of fundamental importance.⁶ quality of life should be judged according to the patient's and their family's perspectives, and not according to the view of the team of professionals who are providing care. Improvements in the quality of end-of-life care assessed according to patient perspectives and priorities. Some studies have been published on this topic, but the literature remains scarce.³⁸⁻⁴⁰

Once the process has been defined as irreversible, decisions should be taken on which therapeutic measures will prioritize the comfort of child during these last moments of their life. This is a shared (consensual) decision between the family and medical team. However, at no point should the family be placed in a position where they have to deal with the responsibility of having decided on the death of their beloved relative. Limiting the life support given to a patient with irreversible disease is a decision made in accordance with

medical guidelines, taking into account the beneficial and collateral effects of each intervention, and also the possible course of the disease, identifying those LSL practices which would best meet the child's interests.

Care of terminal patients begins with a search for consensus within the medical team. Only after everybody involved is convinced and in agreement with relation to the prognosis will discussions be initiated on the future actions to be taken. Very often this process is slow, requiring many meetings which ebb and flow. Confident patients and their family members should be kept adequately informed, and their doubts should be listened to and answered with precise information.

One of the most frequent errors in this situation is to discuss LSL proposals without everybody involved being absolutely convinced of the irreversibility of the process. This inversion of the progress of discussions can have tragic consequences, both within the medical team and between the family and the team, such as a loss of confidence, fantasies as to the real intention of each medical procedure and a radicalization of positions, among others. Therefore, the discussion of possible solutions or decisions should only be taken forward after understanding and acceptance of the irreversibility of clinical status. After this, discussions can be initiated on the conduct and procedures to be employed.

From an educational point of view, we can sum up the progress of practices when faced with terminal patients in the following stages:

Initiation of discussion (and definition) of irreversibility

Discussion should begin and be encouraged within the medical team. The determination of irreversibility is normally based on objective criteria (for example, an inoperable metastasis of the brainstem); on subjective criteria (absence of response to medication); and even, on intuitive criteria (previous experience with similar cases. Obviously, the less objective criteria available, the more difficult it is to reach consensus within the care team and, the longer it takes to become convinced. As a result of the criteria adopted, it should be pointed out that doctors do not always agree on and accept irreversibility at the same time.

Only once consensus has been achieved within the medical team should an encouraging relationship established for the discussion of prognosis with the patient or their representative. How could a family understand LSL practices being applied to a member of their family if the doctors still have doubts or do not agree with relation to diagnosis and prognosis?

Explaining prognosis

The information provided should be presented with the maximum precision possible, in an objective manner, with explanations on the clinical course and potential secondary conditions which may occur. At this point, actions are not being decided upon, the patient and/or their family are merely being presented with the conclusions of the medical team in the light of the perspective of cure and the foreseeable future developments. Evidently, the medical team's arguments will be tested for consistency, reliability and coherence. They should be prepared to return to the discussion many times, as necessary.

It is when LSL has been decided on, that the relationship of confidence between the medical team and family will face its greatest test. Families and patients will be anxious that their doctor has a precise serene and assured technical posture. At the same time, physicians must demonstrate their solidarity, have a great capacity for listening and be able to stimulate verbalization of anxiety and doubts.

The extent and impact of the decisions taken at these meetings demand an environment of privacy, with sufficient time for families to express their doubts and with a circle of people restricted to those most involved in the care of the child. It is inconceivable that such decisions be taken in the corridor of a hospital or that a doctor may be abruptly interrupted to deal with another commitment.

Probably this is one of the major reasons that explain the low level of family participation in the LSL decision-making process in studies undertaken in Brazil and South America.^{20,31-33} this participation presupposes that the doctor's time and availability to discuss and re-discuss the subject many times with the family, but certainly this is neither an inadequate or disproportional demand. It is impossible to expect that family will accept a diagnosis of irreversibility in the case of their child in a passive manner, without first exhausting all other possibilities.

Identification of end-of-life goals

Once consensus on the irreversibility of the process has been arrived at between the medical team and the family, a clear and open discussion is initiated on the medical care desired and goals for the rest of life.

It is important to recognize that, as death grows closer, the majority of patients share the same goals: maximum time with family and friends, avoiding unnecessary hospital admissions and procedures, maintaining functionality and minimizing pain.

For children in hospital, it is of fundamental importance to offer an environment of privacy, which allows permanent contact with families and is far from the agitation that prevails in the majority of our PICUs and emergency rooms. At this

point, laboratory tests, routine procedures and curative interventions should be withdrawn or their utility or futility discussed. The medical team should always be receptive to continue explaining all doubts surrounding each medical practice adopted.

Developing a treatment plan

Based on diagnosis, progress, prognosis and type of immediate complications, the physician should clearly and objectively define what are the palliative priorities to be adopted. It is to be expected that the physician will record on the medical record recommendations considered scientifically appropriate and which, from a humanitarian point of view, are fair, and, from a moral and ethical standpoint, allow a dignified end of life.

If we imagine the example of a patient with widespread cancer, refractory to treatment and with cerebral metastases who is being treated in a hospital PICU, receiving analgesia and IV fluids. The medical record should clearly state that, in the event of apnea, the medical team, in agreement with the family, has decided not to initiate mechanical ventilation. It is unreasonable that these last moments be replete with suffering on the part of the child or their family. Therefore, it is expected that the treating doctor records, also in a clear manner, the conduct that will be adopted (for example, "in the event of respiratory difficulty, increase her infusion, aiming to increase sedation and exclude sensations of dyspnea").

Situations in which consensus cannot be reached

In certain situations conflict occurs between the medical team and the family, the relationship of confidence is broken and positions become radicalized (family autonomy vs. medical autonomy!). In these cases it is recommended that a disinterested mediator be brought in, who has experience and can count on the respect of both "sides". The head of the PICU or the head of the service or department or, even, the Ethics Commission could conduct this conciliation process.

In the majority of cases what occurs is not a loss of confidence, but a failure of communication during one of the previous stages. As tension is reduced, the capacity returns to center discussions on practical aspects that prioritize the best care for that child with an irreversible disease. Happily, cases that require judicial rulings are rare in our country.

Knowledge of the philosophical principles alone, or the application of universal norms in isolation do not guarantee that ethical decisions in PICUs will be taken adequately. The correct decision is the fruit of a process that must take into account the social and cultural context within which it is taken. It is up to the pediatric intensive care specialist to encourage and guarantee that all those involved will participate in this complex decision-making process, aiming to offer the best end-of-life care possible to their patients.

References

- Garros D, Rosuchuk R, Cox P. [Circumstances surrounding end of life in a pediatric intensive care unit](#). *Pediatrics*. 2003;112:371-9.
- Callahan D. [Living and dying with medical technology](#). *Crit Care Med*. 2003;31:S344-6.
- Mateos C, Lopez PR, Diaz JS, Casado R, Holfeinz SB, Fuente AL, et al. [Cuidados al final de la vida en la unidad de cuidados intensivos pediátrica](#). Revisión de la bibliografía. *An Pediatr (Barc)*. 2006;63:152-9.
- Prendergast T, Claessens M, Luce J. [A national survey of end-of-life care for critically ill patients](#). *Am J Resp Crit Care Med*. 1998;158:1163-7.
- Vernon DD, Dean JM, Timmons OD, Banner W Jr., Allen-Webb EM. [Modes of death in the pediatric intensive care unit: withdrawal and limitation of supportive care](#). *Crit Care Med*. 1993;21:1978-802.
- Calet J, Thijs L, Antonelli M, Cassel J, Cox P, Hill N, et al. [Challenges in end-of-life care in ICU. Statement of the 5th Internacional Consensus conference in Critical Care: Brussels, Belgium, April 2003](#). *Intens Care Med*. 2004;30:770-84.
- Truog RD, Cist AFM, Brackett SE, Burns JP. [Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine](#). *Crit Care Med*. 2001;29:2332-48.
- Prendergast T, Luce M. [Increasing incidence of withholding and withdrawal of life support from the critically ill](#). *Am J Resp Crit Care*. 1997;155:15-20.
- Garros D. [Uma boa morte em UTI pediátrica: isso é possível?](#) *J Pediatr (Rio J)*. 2003;79:S243-54.
- Truog RD, Meyer E, Burns JP. [Toward interventions to improve end-of-life care in the pediatric intensive care unit](#). *Crit Care Med*. 2006;34:S373-9.
- Mink B, Pollack M. [Resuscitation and withdrawal of therapy in pediatric intensive care unit](#). *Pediatrics*. 1992;89:961-3.
- Keenan HT, Diekema DS, O'Rourke PP, Cumminngs P, Woodrum DE. [Attitudes toward limitation of support in the pediatric intensive care unit](#). *Crit Care Med*. 2000;8:1590-4.
- Gajewska K, Schoreder M, De Marre F. [Analysis of terminal events in 109 successive deaths in a Belgian intensive care unit](#). *Intensive Care Med*. 2004;30:1224-7.
- Sprung C, Eidelman LA. [Worldwide similarities and differences in the foregoing of life-sustaining treatments](#). *Intensive Care Med*. 1996;2:1003-5.
- Vincent JL. [Forgoing life support in western European intensive care units: the results of an ethical questionnaire](#) *Crit Care Med*. 1999;27:1626-33.
- Cuttini M, Nadai M, Kaminski M, Hansen G, de Leeuw R, Lenoir S, et al. [End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries](#). EURONIC Study Group. *Lancet*. 2000;355:2112-18.
- Devictor D, Nguyen DT. [Forgoing life-sustaining treatments in children: a comparison between Northern and Southern European pediatric intensive care units](#). *Pediatr Crit Care Med*. 2004;5:211-5.
- Yaguchi A, Truog RD, Curtis JR, Luce LM, Levy MM, Melot C, et al. [International differences in end-of-life attitudes in the intensive care unit: results of a survey](#). *Arch Intern Med*. 2005;165:1970-5.

19. Willems DL, Daniels ER, Van der Wal G, van der Maas G, Emanuel EJ. Attitudes and practices concerning the end of life: a comparison between physicians from the and from the Netherlands. *Arch Intern Med.* 2000;16:63-8.
20. Kipper DJ, Piva JP, Garcia PC, Einloft PR, Bruno F, Lago P, et al. Evolution of the medical practices and mode of death on pediatric intensive care units in Southern Brazil. *Pediatr Crit Care Med.* 2005;6:258-63.
21. McLean RF, Tarshis J, Mazer CD, Slazai JP. Death in two Canadian intensive care units: institutional differences and changes over time. *Crit Care Med.* 2000;28:100-3.
22. American Academy of Pediatrics. Committee on Bioethics: guidelines on foregoing life-sustaining medical treatment. *Pediatrics.* 1994;93:532-6.
23. Informed consent, parental permission, and assent in pediatric practice. Committee on Bioethics, American Academy of Pediatrics. *Pediatrics.* 1995;95:314-7.
24. American Academy of Pediatrics. Committee on Bioethics: ethics and the care of critically ill infants and children. *Pediatrics.* 1996;98:149-52.
25. Beauchamp TL, Childress DL. Respect for autonomy. In: Beauchamp TL, Childress JF, editors. *Principles of biomedical ethics.* New York: Oxford University; 1994. p. 120-88.
26. Devictor DJ, Nguyen DT; Groupe Francophone de Reanimation et d'Urgences Pédiatriques. Forgoing life-sustaining treatments: how the decision is made in French pediatric intensive care units. *Crit Care Med.* 2001;29:1356-9.
27. Zawistowski CA, de Vita MA. A descriptive study of children dying in the pediatric intensive care unit, after withdrawal of life sustaining treatment. *Pediatr Crit Care Med.* 2004;5:216-23.
28. Mani RK. End-of-life in India. *Intensive Care Med.* 2006;32:1066-8.
29. Hoehn KS, Nelson RM. Parents should not be excluded from decisions to forgo life-sustaining treatments. *Crit Care Med.* 2001;29:1480-1.
30. Frader J E. Forgoing life support across borders: who decides and why. *Pediatr Crit Care Med.* 2004;5:289-90.
31. Althabe M, Cardigni G, Vassallo J, Allende D, Berrueta M. Dying in the intensive care unit: collaborative multicenter study about forgoing life-sustaining treatment in Argentine pediatric intensive care units. *Pediatr Crit Care Med.* 2003;4:164-9.
32. Lago P, Piva JP, Kipper D, Garcia PC, Pretto C, Giongo M, et al. Limitação de suporte de vida em três unidades de terapia intensiva pediátrica do sul do Brasil. *J Pediatr (Rio J).* 2005;81:111-7.
33. Toneli H, Mota J, Oliveira J. Perfil das condutas médicas que antecedem o óbito de crianças internadas em um hospital terciário. *J Pediatr (Rio J).* 2005;81:118-25.
34. Moritz RD, Pamplona F. Avaliação da recusa ou recusa de tratamentos considerados fúteis ou inúteis em UTI. *Rev Bras Terap Intensiv.* 2003;15:40-4.
35. Pochard F, Azoulay E, Chevret S, Vinsonneau C, Grassin M, Lemaire F, et al. French intensivists do not apply American recommendations regarding decisions to forgo life-sustaining therapy. *Crit Care Med.* 2001;29:1887-92.
36. Sprung CL, Cohen SL, Sjøkvist P, Baras M, Bulow HH, Hovilehto S, et al. End-of-life practices in European intensive care units. The Ethicus Study. *JAMA.* 2003;290:790-7.
37. Conselho Federal de Medicina. Resolução CFM 1.805/2006. Diário Oficial da União 28 nov. 2006, Seção I, p. 196.
38. Meyer EC, Burns JP, Griffith JL, Truog RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Crit Care Med.* 2002;30:226-31.
39. Meert JL, Thurston CS, Briller SH. The spiritual needs of parents at the time of their child's death in the pediatric intensive care unit and during bereavement: a qualitative study. *Pediatr Crit Care Med.* 2005;6:420-7.
40. Devictor DJ. Are we ready to discuss spirituality with our patients and their families? *Pediatr Crit Care Med.* 2005;6:492-49.

Correspondence:
 Patrícia Miranda Lago
 Rua Furriel Luis Vargas 238/201
 CEP 90470-130 – Porto Alegre, RS – Brazil
 Tel.: +55 (51) 3333.4462, +55 (51) 9678.0431
 E-mail: lagopatrícia@terra.com.br