

# Limitation of pediatric life support: ethical arguments

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## Abstract

**Objectives:** To know the ethical arguments of pediatric intensive care physicians in order to justify decisions in the field of limitation of life support, in a pediatric intensive care unit of the city of Rio de Janeiro, analyzing them critically. **Methods:** This is a descriptive case study. 17 semi-structured interviews were performed with intensive care physicians that worked in a high complexity pediatric intensive care unit in Rio de Janeiro. **Results:** The physicians adopted a paternalistic tendency in the decision making of limitation of life support, and the interviewed people were not aware of its application and the steps of the process. **Conclusions:** Educational activities related to dying process should be encouraged as the dialogue and recognition of others as a moral agent. Bioethics can be useful in this critical development helping the resolution of ethical conflicts not only in the limitation of life support process but also in other areas of medicine.

**Keywords:** Bioethics. Palliative care in terminally life. Pediatrics. Intensive care units. Medical education.

## Resumo

### Limitação do suporte de vida pediátrico: argumentações éticas

**Objetivos:** Conhecer os argumentos éticos de médicos intensivistas pediátricos de uma unidade de terapia intensiva pediátrica da cidade do Rio de Janeiro para justificar suas decisões em casos de limitação de suporte de vida e analisá-los criticamente. **Métodos:** Trata-se de estudo de caso, descritivo. Foram realizadas 17 entrevistas semiestruturadas com intensivistas pediátricos de uma unidade de terapia intensiva pediátrica de alta complexidade do Rio de Janeiro. **Resultados:** Os entrevistados desconhecem a aplicação e as etapas do processo de limitação do suporte de vida, utilizando uma tendência paternalista nas tomadas de decisão. **Conclusões:** Medidas educativas relacionadas com o processo de morrer devem ser incentivadas durante a formação médica, desenvolvendo o diálogo e o reconhecimento do outro como agente moral. A bioética pode ajudar no desenvolvimento crítico desses profissionais, auxiliando na resolução dos conflitos éticos que surgem não só no processo de limitação do suporte de vida, como em outras áreas da medicina.

**Palavras-chave:** Bioética. Cuidados paliativos na terminalidade da vida. Pediatria. Unidades de terapia intensiva. Educação médica.

## Resumen

### Limitación del soporte de vida pediátrico: argumentos éticos

**Objetivos:** Conocer los argumentos éticos de médicos de cuidados intensivos pediátricos de una unidad de cuidados intensivos pediátrica de la ciudad de Río de Janeiro para justificar sus decisiones en los casos de limitación de soporte vital y analizarlos críticamente. **Métodos:** Se trata de un estudio de caso, descriptivo. Se realizaron 17 entrevistas semiestructuradas con los intensivistas pediátricos en una Unidad de Cuidados Intensivos Pediátricos de alta complejidad en la ciudad de Río de Janeiro. **Resultados:** Los médicos entrevistados desconocen la aplicación y las etapas del proceso de Limitación del Soporte de Vida, utilizando en su lugar una tendencia paternalista en la toma de decisiones. **Conclusiones:** Las actividades educativas relacionadas con el proceso de muerte deben ser incentivadas durante la formación médica, para facilitar el desarrollo del diálogo y el reconocimiento del otro como un agente moral. La Bioética puede ayudar al desarrollo crítico de estos profesionales, auxiliándolos en la resolución de los conflictos éticos que surjan, no solo en el proceso de Limitación del Soporte de Vida, como en otras áreas de la medicina.

**Palabras-clave:** Bioética. Cuidados paliativos al final de la vida. Pediatría. Unidades de cuidados intensivos. Educación médica.

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Declararam não haver conflito de interesse.

In a social phenomenon in which the advance in the development of medical sciences field in technologies played an important role, death shifted in the first half of the twentieth century, the family environment for the hospital. The hospital has become the place where medical care can be offered and death becomes *a technical phenomenon caused by the arrest of care, that is, more or less declared way, by decision of the doctor and the hospital staff*<sup>1</sup>.

The intensive care units (ICU) have emerged from the 1950s, with the realization that it was more effective for the care together in a single environment patients who were using mechanical ventilation<sup>2</sup>. Being the hospital site where patients more serious were allocated and more high-tech features, the ICU began to also receive chronic patients, with the hope that the use of these technologies prevent, or at least slowed significantly, his death. This measure, on the other hand, also increased the futile suffering of some sick as a result of excessive use of such technology.

From the 1990s, the quality of care at end of life begins to get more attention, and discussions about ethical issues surrounding this theme, such as therapeutic obstinacy, have become very common in the academic field, but such discussions have not been frequent Brazilian in the academic medical environment<sup>3</sup>. The biomedical model of care associated with the new technological paradigm imposed some professionals the obligation to offer all patients and any techno resource for coping with medical conditions. The true benefits of these actions are often in the background stations, inflicting pain and suffering to patients, without having reached a satisfactory result in terms of cure or disease control, which is described as dysthanasia<sup>4,5</sup>.

We must be clear that the great development of the medical service technology is a relatively recent phenomenon, which starts around the 1960s. This technological development, whether in the form of new drugs or diagnostic and therapeutic equipment, was accompanied the advancement of new techniques. Thus, the therapeutic intervention capacity in serious patient became immeasurably greater, making it difficult to determine when that technically there is no more how to help a patient, which causes the therapeutic obstinacy and dysthanasia are, more and more possibilities concrete.

The life support limitation process (LSV) is opposed to therapeutic futility, trying to avoid painful death processes. He understands the do not resus-

cite orders (maintenance of all curative measures until death occurs by cardiac arrest), the removal order (suspension of one or more measures that are prolonging the dying process) and the order not offer (not start dressing supportive measures that can prolong the process of death of an individual)<sup>6,7</sup>. Recent studies show an increase in the use of LSV up to 90% in intensive care units<sup>8</sup>. This is also a reality in Brazilian studies, although they have demonstrated, in fact, that more than half of LSV measures correspond only to the order of DNR<sup>6</sup>. The studies in children are not yet very common, but already show that, as in the adult intensive care, up to 72% of deaths in pediatric intensive care units (PICU) were preceded by some limitation measure<sup>9</sup>.

Bioethics, which *is concerned with analyzing the moral arguments for and against certain human practices that affect the quality of life and the welfare of humans and make decisions based on previous analyzes*<sup>10</sup>, can help health professionals to better deal with emerging conflicts in end of life care, facilitating decision-making in that moral issues are properly considered and the decision is well founded.

Considering the lack of studies with this focus, we developed our hypotheses from the practical experience of the authors. We believe that doctors would express the conflict in the decision time of LSV as the tension between the principle of the sacredness of life and the autonomy of the patient and the inappropriate use of resources, taking into account the scarcity of these resources in health systems. Note that our understanding of the principle of sanctity of life is in line with the expressed by Diniz, which distinguishes the principle of sanctity of life. *The sacredness is a secular principle ensuring the moral value of human existence and justifies different social mechanisms that guarantee the right to be alive. [...] Recognize the moral value of human existence is not the same as believing their untouchability. The principle of sanctity of life is dogmatic foundation and religious*<sup>11</sup>.

## Method

This was a case study, descriptive, it was taken as an object of analysis the lines of pediatric critical care physicians, hired by a private clinic in the city of Rio de Janeiro to work on your PICU, on life support limitation.

No data information available on the number of PICU or even on the number of jobs. The Brazilian Institute of Geography and Statistics provides data aggregated by city, but does not distinguish the intensive care unit of the pediatric adults. The best information available to the Rio de Janeiro is offered by Barbosa, with data obtained on a visit to each of the establishments. That meeting identified in the metropolitan region of the state only 11 intensive care units intended exclusively for pediatric patients and 25 mixed units. The number of beds available at the end of the last century was 59 unique to pediatric patients and 223 mixed<sup>12</sup>.

Doctors were the study subjects chosen for this study because they represent the central figure in the decision of life support limitation process. Was selected for this study a pediatric intensive care unit of high complexity clinical private sector of the city of Rio de Janeiro. The choice of this clinical aimed to ensure greater possibility of practical occurrences of life support limitation.

As there are few such units in the city of Rio de Janeiro and most professionals working in PICU works in more than one unit, it was understood that this unit was appropriate for the case study. Reinforces the possibility of extending the information in the same way, the fact that the work processes and the way work is organized in PICU not differ essentially from one unit to another, being composed of both attending physicians and by physicians practicing routine function of the service, who come daily to the unit.

The PICU studied there were 16 physicians with a workload of 18 hours distributed in shifts of 12 hours per week, one on duty during the day and two on duty at night, with relay in shifts of 12 hours at the end of alternate weeks. The service also had three journeymen doctors who performed their duties in the morning and afternoon, so that during the day there was always one on duty in the PICU and at least one medical routine. The situation of all patients, as well as the schedule of exams and their behavior according to their clinical status and diagnosis, was discussed between physicians and day laborers in "rounds" daily which also counted on the participation of duty nurse, physiotherapist and psychologist.

The principal investigator of this study is one of 19 pediatric intensivists working in selected PICU. This prior knowledge of the study subjects may have hindered the reporting practices that were likely to

be illegal or unethical. The guarantee of confidentiality was reinforced in order to control this potential bias, which is why confine the specific information about the respondents and even more particularized description of the PICU. Another possible bias was the fact that, at the time of field research, only be women hired for this function in this clinic. Thus, the absence of men among respondents prevents examination of gender differences in the decision-making process.

Interviews were conducted in the workplace of professional in Your chosen by them, outside their regular period of activity. 17 semi-structured interviews with pediatric intensivists were performed. It was clarified that the medical questions would refer not only to decisions that the chosen drive, but also to those taken in any PICU in which the patient has exercised professional activity. The interviews took place between the months of September and October 2010, after permission for audio recording and signing the free and informed consent. The interview consisted of a first part, on data from academic and professional activity of professional, followed by open questions about the practice of LSV. The data analysis was performed according to the content analysis technique developed by Bardin<sup>13</sup>.

In the questionnaire prepared for the research, there was a group of questions focused on identifying situations that would be justified, the interviewee's point of view, life support limitation and a second group of questions that tried to identify the values on which the medical relied for making such a decision. After the initial reading, it was held the first contact with the text, repeated readings allowed the recognition and the creation of categories for analysis and identification of the theoretical framework of bioethics in the arguments put forward to justify or not the suspension of the life support of patients.

## Results and discussion

17 of the 19 physicians who worked in the chosen unit were interviewed. An intensivist was not interviewed for being on sick leave and the other, as reported, for being the principal investigator of the study. The age of respondents varied from 30 to 55, and most of them had more than ten years since graduation. Medical nine attended medical school at public universities. All interviewees have pediatrics as specialization and nine had postgraduate pediatric intensive care, including all those under ten years

formed. Six interviewees also attended other specialization. Thirteen medical exercised, during the study period, the function of pediatric intensivists in one or more units beyond chosen for the study, and all interviewees had already had the experience of exercising this function in PICU public sector.

All respondents considered the limitation of life support difficult subject and delicate. Although some studies show that more than half of the deaths in the PICU is preceded by some measure of LSV<sup>9</sup>, seven women reported never having heard of the term. When asked to define the concept, all did as synonymous not to *resuscitate and / or do not offer new therapies*. Although the order of non-supply and treatments suspension order that will not be sufficient to recover the well-being of a patient are morally equivalent, none of them has considered the possibility of suspension of any therapy, even when asked directly about the fact. Eleven of the 17 interviewed admitted having practiced the LSV, but more than half only in specific situations. Of those who refused to practice three knew the term. Most situations where the LSV was suggested referring to children with brain death.

The standards for diagnosis of brain death were published in 1997 by the Federal Council of Medicine and deal with the withdrawal of life support those patients with confirmed brain death whose family was communicated and who are unable to become organ donors<sup>14</sup>. The withdrawal of support in this case is even support cool. However, the concept of life support limitation relates to process support limitation those patients still alive and, therefore, does not apply to patients with brain death. This lack of concepts, or perhaps the fear of some punishment, ultimately generates unnecessary suffering in families and spending to the responsible for the costs of hospitalization, is the very family of the patient, is the Unified Health System, is the health insurance .

As the theory of the four principles or principlism of Beauchamp and Childress<sup>15</sup> the hegemonic power of bioethics in the world, including with regard to international research publications, we believed that ethical arguments used by the interviewees, if present, would refer to the principles of this current . All interviewees mentioned expressions that reflected more of a principle in decision-making, but only one of them mentioned the four principles, using the name. This medical attends meetings of a bioethics committee at another hospital. The mention of principles such as non-maleficence and beneficence seems to be related to the

Hippocratic tradition, and not with the principlism proposed by Beauchamp and Childress.

The non-maleficence was the most this principle in the discourses of medical, cited by 13 of the 17 interviewed. There is a clear concern on the part of them, with painful procedures imposed on patients. According to related articles, that should be the principle determinant for choosing therapeutic approaches in cases of terminal illness<sup>16</sup>. This principle, in this Hippocratic thinking first not cause evil (*primum non nocere*), seems to be the main justification of pediatric intensivists participants for not offering treatments considered futile for patients with end-stage, but does not seem strong enough to justify the suspension of such treatments. All respondents reported that they were based on the principle of non-maleficence in their decision making, three of which, paradoxically, admitted having practiced measures that could be recognized as futile.

The charity, considered by doctors the moral basis of his actions, was mentioned in only 9 of the 17 interviews. Many doctors, concerned about “doing good” to their patients, interpret this expression as the obligation to use all the therapeutic arsenal available to all patients and end, in fact, causing dysthanasia those considered terminally ill. Most doctors say that make use of this principle simultaneously uses the non-maleficence as a way to weigh risks and benefits to determine the treatment to be used more, which is in accordance with the tradition of medical ethics, expressed in two precepts present from the Oath Hippocrates: *I will apply the schemes for the benefit of the sick according to my ability and understanding, never to harm or hurt someone*<sup>17</sup>.

Pediatric study about the end of life conducted in Brazil showed that the principles of beneficence and non-maleficence were used in 83% of cases compared to only 50% of quotes about quality of life<sup>16</sup>. In the present study, 12 of 17 respondents mentioned the quality of life as the argument considered when deciding. But these 12, only 2 doctors said that quality of life should be judged by the individual himself, which is difficult in the case of patients without full autonomy as children. All other medical 10 said they used objective factors to judge quality of life, such as the ability to perform certain tasks and forms of interaction with the environment, in an attempt to become more impartial evaluation.

The idea shared by the interviewees is that neither the parents nor any legal representative would be able to better defend the best interests of children than the doctors themselves, although this

position is contrary to Brazilian law, which mandates the participation of children and adolescents, alone or in the company of parents or their representatives, in acts of measures related to the promotion and protection of their rights, should their opinions be necessarily considered<sup>18</sup>. The implicit paternalism in this position is unjustifiable fact if we understand that the effort put yourself in the other will be useless, given the inability to effectively understand what the other with his life experiences and values, considers best for you and what can actually be better for it.

The excessive use of technology, scarce resources and a lack of intensive care unit beds lead many authors to use the principle of justice as the basis for decision-making in cases of LSV. In 2004 Turret observed, when performing a search in Brazil on the management of patients with end-stage, 72% of physicians cited the inappropriate use of resources as an element that contributed to the decision on life support limitation<sup>16</sup>. According to some researchers, justice, even as a relevant principle, should not be used as a determinant for this decision, because, more than economic indicators, the decision on limiting the life of a patient with end-stage encompasses the patient's own subjective values<sup>3,5,16,19,20</sup>.

This theoretical approach seems to come to the meeting from the perspective of the respondents, as only 3 of the 17 participants in this study mentioned actions that would have founded on the principle of justice. Just as was observed in the reported studies, none of our interviewees considered this principle as a decisive factor in decision making. This finding can be explained by a possible misunderstanding about when it is appropriate to consider the principle of justice in health care. We did not have enough information to this analysis, it is possible only to formulate an explanatory hypothesis.

Decisions regarding the LSV must be taken to the individual assessment of each patient. Cultural, religious, benefits and quality of life judgments are subjective criteria that require tolerance and reflection by all those involved in the process<sup>21-24</sup>. Only four respondents recognized that the LSL decision should be made case by case, with no situations in which this decision can be taken without exception. Despite the recommendation that all staff participate in the process as well as the patient and the family, only six were interviewed mentioned that the LSV must be decided with the help of a multidisciplinary team. The eleven other medical professionals said they believed other than physicians and

the family eventually disrupt the process, making it unproductive.

However, unlike the one found in this study, we consider that the participation of other professionals in the deliberative process ensures a cohesive decision, if not obtained, may favor the emergence of conflicts, making the relationship with the family and the treatment plan of the patient. This attitude of the respondents confirms the omnipotent image that the doctor has to itself, little tolerant of dissenting views. The trial of moral values, an important step in this process, independent of great theoretical knowledge, but demands respect and tolerance<sup>25</sup>.

Family participation in LSV process was considered important for all medical. However, in the case of discordant opinions among family and doctor, only two interviewees maintain the treatment offered and insist the agreement. For the other, the medical decision must prevail over that of the family.

The asymmetric position between the power of the medical decision and the family that often emerges in the discourse of the interviewees, was marked by subterfuge intended to make his views prevail, as not being explicit about the proposed treatment, while offering therapeutic measures do not think, from his point of view, valid. Added to this interpretation itself that makes the expression "*I do not want to remove anything*," many parents are pronounced as a way to speak out against LSV measures and what the interviewees mean not as a prohibition on the removal order, but as permission for orders not offer and not to resuscitate.

Some of the reasons mentioned by the interviewees to justify this attitude were "*family side problems in doctor-family binomial*", which, according claimed, manifested in the intellectual inability of parents to understand the real state of the children or their great emotional involvement. The possible guilt that parents would experience for deciding the death of children is also a justification given in the laws and regulations of some countries to legitimize the medical paternalism<sup>21,26</sup>. However, US research shows that 85% of families would like to have the final say during the LSV your family and that the grieving process is better prepared those parents who accompanied the treatment and participated in discussions on life support limitation<sup>27</sup>. the justification of the family intellectual disability may actually hide the low quality of communication between doctor and patient and family-be the reason for the emergence of conflict during the LSV.



The paternalistic position adopted by most of the respondents confirms the medical knowledge on the topic LSV and reinforces the idea that doctors themselves as the most capable people to make the right choice, even if that choice involves subjective values of hard trial. Models of substitute decisions, such as the best interest created by Beauchamp and Childress<sup>15</sup>, when the selected attitude should be directed to the best option for the child, can not respond to this conflict in the decision by third parties and mischaracterize according to point of view of the authors of this article, the concept of autonomy.

Only one respondent said that the patient should participate in the decision-making process, which suggests that other interviewees consider them not self-employed people, whose legal decision-making power is centered on the figure of the parents. This reinforces the habit that pediatricians have not consult children, whenever possible, on issues related to their health. The Declaration of Monaco<sup>28</sup>, drafted in 2000 at the international symposium on bioethics and children's rights, advises that children should take part in decision making about their health, increasingly as the development of their autonomy and, consequently, the doctors should always seek the consent of pediatric patients. In Brazil, the Statute of Children and Adolescents and the Civil Code also standardize the participation of the child and his family in decision-making<sup>18,29</sup>.

Many respondents believe that the regulation of pipelines on a terminal patient could facilitate the reasoning in decision making on the LSV. However, the existence of protocols by Topic is unable to respond to ethical conflicts such cases. What to do to judge what is "best for the other," what is quality of life or who has the final word are questions whose answers are not in protocols. It is necessary to weigh on values, a process that does not involve fixed criteria and requiring case-by-case.

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## Final Considerations

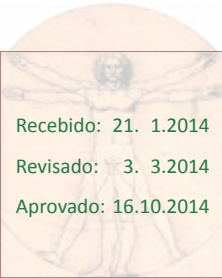
The arguments we thought that would be used by the interviewees were not confirmed. Pediatric intensivists interviewed in this study, despite using expressions which refer to the principles of principlialist chain, did not seem to be familiar with the fundamentals of this theory. In their responses, showed great concern not disrespect what suppose to be the legal prohibition of life support limitation, although they do in their practices. On the other hand, declared disregard the legal principles that acknowledge having parents and minors, within the limits of its powers, the right to decide on facts and events of their lives. Questioning from the emotional balance of the parents to their technical knowledge, they seem to claim the technical authority and a consequent moral authority to decide on behalf of their patients even when they should die without considering essential that other stakeholders participate in the decision.

Paternalism expressed in the interviews has its roots in the very formation of the Brazilian State and democratic fragility of our country, that only after the promulgation of the 1988 Constitution now has legislation that protects the individual and collective rights of citizens. Although the legislation is already available, it will take a while until these rights are effectively guaranteed to all. Such difficulties are also manifest, as seen in professional relationships between doctors and patients. Also in this field are needed specific action in the event of an educational nature, so that discussions about death, dying, dysthanasia and the autonomy of patients are not as superficial as has been demonstrated. Bioethics can be an important tool in this process by allowing greater investment in discussions about the moral aspects of professional practice, seeking the formation of professionals committed to dialogue and respect for human rights.

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#### Participação dos autores

Grace Kelly Paranhos – concepção e delineamento do estudo, revisão bibliográfica, realização do trabalho de campo, análise dos dados, redação do artigo. Sergio Rego – concepção e delineamento do estudo, análise dos dados, redação do artigo e revisão crítica.



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Annex

Interview script

• Date of birth: \_\_\_\_\_

• Sex: \_\_\_\_\_

• Year of medical graduation graduation? \_\_\_\_\_  
Faculty: \_\_\_\_\_

• Specialization in pediatrics?  
( ) Yes  
( ) No  
( ) Residence  
( ) Especialization  
( ) Other. Which? \_\_\_\_\_

• Training in pediatric intensive care?  
( ) Yes  
( ) No  
( ) Residence  
( ) Especialization  
( ) Other. Which? \_\_\_\_\_

• Training in another specialty?  
( ) Yes. Which? \_\_\_\_\_  
( ) No

Title specialist in pediatric intensive care?  
( ) Yes Year: \_\_\_\_\_  
( ) No

• Specialist Title in another specialty?  
( ) Yes. What? \_\_\_\_\_  
( ) No

• How many pediatric intensive care units you work?  
What are the characteristics of these units?  
1st                      2nd                      3rd  
( ) Public              ( ) Public              ( ) Public  
( ) Private              ( ) Private              ( ) Private  
( ) Pediatric              ( ) Pediatric              ( ) Pediatric  
( ) Neonatal              ( ) Neonatal              ( ) Neonatal  
( ) Miscellaneous ( ) Miscellaneous ( ) Mixed

• What do you consider limitation of life support?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• You have limited life support a child? Why? In that situation?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• It has happened to limit life support a pediatric patient in a service that you work? What was the situation?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• These decisions were recorded in the medical record? Why? In what situations do you think these decisions should be recorded in the medical record?  
\_\_\_\_\_  
\_\_\_\_\_

• Do you think there is any situation where it is appropriate life support limit? Which one (s)? Why? Why in some situations you think is reasonable support of the limit of life and not others? What makes the difference between these situations in order to make it acceptable in some situations and not others? Why do you think that it is never acceptable / justifiable? Why do you think that is always acceptable / justifiable choose life support limitation?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• Who do you think should participate in these decisions? What should be the role of medical staff in these decisions? And the family? And the patient?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• In your opinion, what values should guide decision making in these kinds of situations? Why?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• Do you think, with regard to the life support limit, that its decisions are different when you are working in public or private services? And other medical?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

• During his undergraduate medicine, you had the opportunity to discuss ethical dilemmas?  
( ) Yes  
( ) No  
And on life support limit? \_\_\_\_\_  
\_\_\_\_\_  
( ) Yes  
( ) No



And in his training in pediatrics? \_\_\_\_\_

- Yes  
 No

And in his training in pediatric intensive care?

- Yes  
 No