

Limitação do suporte de vida em unidade de terapia intensiva pediátrica

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Resumo

O presente estudo resulta de revisão de prontuários de pacientes falecidos no período de quatro anos em UTI pediátrica de hospital universitário, tendo analisado variáveis como tempo de internação, diagnóstico da principal falência orgânica da criança, ocorrência de doenças crônicas prévias, tomada de decisões dos médicos referentes à introdução de medidas de suporte vital de vida, ordens de não reanimação e qualidade da relação dos profissionais com familiares dos pacientes. Os resultados sugerem que as condutas adotadas pelos médicos refletem majoritariamente a preocupação de se protegerem contra eventuais processos judiciais decorrentes da acusação de omissão de socorro. Embora os casos clínicos estudados refiram-se a pacientes portadores de enfermidades terminais, o que por si só envolve complexos conflitos morais, em nenhum momento foi oferecido aos familiares dos pacientes a possibilidade de participarem dos processos de decisões médicas e, tampouco, existem registros de consultas ao comitê de ética do hospital.

Palavras-chave: Cuidados médicos. Cuidados paliativos na terminalidade da vida. Unidade de terapia intensiva. Pediatria. Leis-Crime-Brasil. Legislação.

Resumen

Limitación del soporte de vida en unidad de cuidados intensivos pediátricos

El presente estudio es el resultado de una revisión de registros de pacientes fallecidos en el período de tres años en la UCI Pediátricos de un Hospital Universitario, se ha analizado variables como tiempo de permanencia en el hospital, diagnóstico de la principal falla orgánica del niño, la toma de decisiones de los médicos con respecto a medidas de soporte de la vida, órdenes de no reanimación y la calidad de la relación de los profesionales con las familias de los enfermos. Los resultados muestran que las conductas adoptadas por los médicos reflejen principalmente la preocupación de ellos en protegerse de posibles demandas judiciales por cargo de omisión de socorro. Aunque los casos clínicos estudiados se refieran a pacientes con enfermedades terminales, lo que a su vez enredase en complejos conflictos morales, en ningún momento fue ofrecido a los familiares de los enfermos la oportunidad de participar del proceso de la toma de decisiones médicas y, tampoco hay registro de consultas a la Comisión de Ética del Hospital.

Palabras-clave: Atención médica. Cuidados paliativos al final de la vida. Unidades de cuidados intensivos. Pediatría. Leyes-Crimen-Brasil. Legislación.

Abstract

Limitation of life support in the pediatric intensive care unit

The present study has been made through a revision of medical reports during the period of three years at the Pediatric Intensive Care Unit of a University Hospital, having analyzed the variables as, hospitalization time, diagnosis of the child's principle organ failure, presence of chronic disease, the doctor's decision concerning the introduction of life support measure, the do-not-resuscitate (DNR) orders additionally the relationship quality towards doctors and relatives. Most of the obtained results revealed that the procedures adopted by doctors reflect majorly the professional concerns to protect themselves from lawsuits about neglecting help. Although, the clinic cases studied refers to patients carriers of terminal illness, which only by itself, involves an enormous quantity of moral conflicts, at none of these situations were offered to the patient's relatives the possibility to participate at the deliberately procedures about the medical decision therefore there were no consultations with the Ethics Committee from the Hospital.

Key words: Medical care. Hospice care. Intensive care units. Pediatrics. Laws-Crime-Brazil. Legislation.

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Declararam não haver conflito de interesse.

The progress of medicine in the last decades brought many benefits to human health, such as the eradication and control of infectious diseases, the reduction of child mortality and the increase of life expectancy^{1,2}. While in the beginning of the last century dying was recognized as a natural process that usually occurred at home, the contemporary society describes this fact with circumstances of extreme suffering and prolonged agony³. Nowadays, doctors and patients live together in the intensive therapy units with top-notch technologies of artificial life support, that if used in a reckless manner can result in therapeutic obstinacy^{4,5}.

This scenario was well described by the metaphor suggested by Pessini: *our intensive care units (ICUs) are the modern cathedrals of human suffering*⁶. Critical reflections about the end-of-life accompanied by inexplicable suffering started to be described in medical literature since the 1990's, starting a broad ethical and moral discussion about the excessive use of technology in the final moments of existence^{7,8}.

There's a great variability in the decision-making about the end-of-life adopted in many countries and even among units from the same country. European studies about deaths followed by interventional procedures in terminal patients show variable rates: 23% in Italy and 51% in Switzerland⁹, for example. Another observational study of 131 ICUs in the United States of America (USA) showed that the non-offering of life support (Nols) ranged from zero to 67%, and the withdrawal of life support (WLS), from zero to 79%¹⁰. The number of studies related to the limitation of life support (LLS) in pediatric ICUs is less numerous, because the mortality is relatively low and the expected healing, high; what makes that, in the majority of the studies, in these cases the attitudes towards end of life are proposed very late, only when all possibilities of recovery have already been proved inefficient¹¹.

Modern society considers a disorder of nature that children die before their parents, what makes the death of a child an unacceptable loss. As a result, the grieving process is very painful, making inconceivable any limitation in the treatment of those patients, despite the diagnosis and prognosis of the disease^{12,13}. In Brazil, Kipper¹⁴, Carvalho¹⁵ and Lago¹⁶ are researches that are part of the group of authors that have published studies about the limitation of life support in Pediatrics. In a thesis presented to the Medicine College from University of São Paulo (USP), which objective was to evaluate the therapeutic attitude adopted by intensive care doctors from 11 intensive care units from the Hospi-

tal das Clínicas complex in the aspects related to the medical care given to adults with terminal illnesses, it was found that the practice of disproportionate procedures is very common¹⁷.

The objective of the this study was to get to know the occurrence of limitation of life support in pediatric ICU from the University Hospital of State University of Londrina (HU/UEL), in the period of four years. Between the variables studied stood out the medical attitudes towards the end-of-life, the factors related to the limitation of life support and the participation of relatives in the process of therapeutic decision-making suggested by the healthcare team and applied in children.

Method

A transversal descriptive and retrospective study was conducted by the revision of medical records from all patients that died in the period of January/2000 to December/2003, in pediatric ICU from HU-UEL. The project was previously approved by the Ethics in Research with Human Beings Committee (ERHBC) from the institution.

The data collected makes reference to the characteristics of patients, hospitalization time, hospitalization time in pediatric ICU, diagnosis from the main organic failure registered in the hospital admission, existence of chronic diseases, participation of relatives in the decisions towards the end-of-life, consultation with the Ethics Committee from the hospital and the type of death. The variables that refer to the condition of death were classified as: failure of cardiopulmonary resuscitation maneuvers (CRM), brain death (BD), do-not-resuscitate (DNR) orders, non introduction and withdrawal of life support procedures¹⁰.

The data collected by the research was submitted to association and chi-squares tests, considering 5% of significance level. The data was analyzed by the Statistical 7.1 and SAS 9.1. The continuous variables were represented by the average and dispersion, and the ones that presented unusual values were presented by the median and chi-squares intervals. The qualitative variables were expressed in percentages with the use of tables. To the univariate analysis was used the chi-square test. In the multivariate analysis the logistic regression was used, employing the method of variables selection to explain the variable answer, *stepwise* of Hosmer e Lemeshow¹⁸. In both cases, the level of significance was 5% or, in other words, descriptive value < 0,05.

Results

In the period addressed by the study, 989 admissions in the pediatric ICU of HU-UEL occurred. From these, 151 died. Three cases were excluded from the study by lack of appropriate documentation. From the other 148 patients, 54% were male children e 46% female. The average age of patients was 25 months, with median of seven months. The average length of hospitalization time was 16 days, and 11 days for ICU (Table 1). More than half of deaths (64%) occurred in patients previously diagnosed with chronic diseases. In 33 cases (22%) death occur in the first 24 hours of ICU admission. The incidents of respiratory (41%), cardio circulatory (32%) and neurological (16%) failure were the main causes of hospitalization.

Table 1. Characteristics of deaths

Admissions (n)	989
Deaths – n (%)	148 (14,9)
Age(months)	
Average ± PD	25 (± 35,1)
Median (25-75%)	7 (7-41)
Gender (male/female)	80:68
Main failure in admission (%)	
Respiratory	41
Cardiocirculatory	32
Neurological	16
Length of hospitalization time (days)	
Average ± DP	16,6 (± 24,4)
Median (25-75%)	7 (2-19)
Length of ped. ICU hosp time. (days)	
Average ± DP	11 (± 17,7)
Median (25-75%)	4 (1-12)
Direct admission in ICU – n(%)	84 (56,7)
Death in the first 24h – n (%)	33 (22)
Existence of chronic illness – n (%)	95 (64)

DP= Desvio padrão.

In only seven cases (5%), the dialogue with the patients’ relatives about attitudes to be taken towards end-of-life was registered in the medical records. From this total, only six received diagnosis of brain death. There’s no record of formal consultation directed to the Ethics Committee of the hospital. From the total cases of limitation of life support, the DNR was recommended in 52. Except from the four patients with brain death, in no other case was registered withdrawal of life support (Table 2).

Table 2. Prevailing ways of dying

Ways of dying	N (%)
FRCP	77(52)
ME	15(10,1)
ONR	52 (35,1)
Nosv	4 (2,7)
RSV	0 (0)

FCPR= failure in cardiopulmonary resuscitation; BD= brain death; DNR= do-not-resuscitate orders; Nols= non offer of life support; WLS= withdrawal of life support.

Seventy-seven deaths (52%) were preceded by CPR maneuvers. Thirty-three deaths occurred in the first 24 hours of ICU admission, but in 32 of them CPR maneuvers were done. The average time of hospitalization was 7,8 days to patients that received CPR and 19,5 days to patients that suffered some type of limitation of life support. In the cases of brain death, that didn’t received permission from relatives for the removal of organs to transplant, the vasoactive medications, anti-biotic therapy and parental nutrition were suspended by medical decision. However, in none of these cases the extubation of patients was performed, maintaining, therefore, the mechanical ventilation support. The cases of brain death were excluded in order to do a more appropriate evaluation of factors related to the limitation of life support. By the univariate analysis, we observed that some factors were related to LLS, such as the length of hospitalization higher than three days and ICU hospitalization higher than 24 hours (Table 3).

Table 3. Univariate analyses from factors possibly related to the limitation of life support

Factors studied	LLS	CPR	Value of chi-Square test
Age			
> 12 months	32	19	p = 0,37
< 12 months	45	37	
Length of hospitalization			
> 3 days	47	10	p = 0,00 (*)
< 3 days	30	46	
Existence of chronic illness			
Yes	41	51	p = 0,39
No	15	26	
Direct admission in ped. ICU			
Yes	29	42	p = 0,75
No	27	35	
Length of hosp.. in ped. ICU			
> 24 hours	55	45	p = 0,00 (*)
< 24 hours	1	32	

LLS= limitation of life support; CPR= Cardiopulmonary resuscitation; (*) p<0,001

The multivariate analysis also showed the significant relationship between LLS and both factors related above, with DNR of 2,86 (CI 95%: 1,10-7,43) to the length of hospitalization higher than three days and of 3,12 (CI 95%; 2,63-194,7) to the length of ICU hospitalization higher than 24 hours (Table 4).

Table 4. Multivariate analysis of factors related to the limitation of life support

Factors studied	OR	CI 95%	"p"
Length of hospitalization > 3 days	2,86	1,10 – 7,43	0,03
Length of ped. UCI Hosp. > 24 hours	3,12	2,63 – 194,7	0,004

OR= odds ratio; CI= confidence interval.

Discussion

The occurrence of deaths preceded by some decision to limit therapeutics in pediatric intensive care units ranged from 30% to 65% in studies published since the 1990's^{7,20-23}. In 2003, Althabe¹⁹ reported the occurrence of 36% LLS in Argentinean pediatric ICUs. In Brazil, in 2005, Kipper showed that in a period of 10 years the occurrence of LLS more than doubled, from 6,2%, in 1988, to 15,8% in 1998¹⁴. In this study, the occurrence of LLS was 38%, a similar result obtained in other Brazilian studies^{15,16,20}. The criteria of limitation of life support that was most used was DNR¹⁴, what suggests a difficulty from the healthcare team in deciding by the limitation or suspension interruption of procedures of life support^{16,19}. The use of CPR maneuvers adopted in Brazil is high (52%) when compared to studies conducted in the U.S., Canada and Western Europe^{9,21-23}. The conditions that probably explain this difference include factors of socio-cultural and religious nature and even the personal experiences lived by members of the healthcare team^{24,25}. It's important to point out that the CPR maneuvers used since the 1960's were originally proposed to deal with cases of sudden death, which is a different situation from the cases analyzed in this study, that had as subjects of the research children with chronic illnesses that suffered cardiocirculatory arrest as a predictable result of the natural evolution of their underlying diseases¹⁶.

The difficulties faced by doctors to make decisions regarding patients with terminal illnesses, as observed in this study, seems to indicate an insecurity of the professionals to conduct cases that involve complex moral conflicts, topics that aren't usually discussed in Medical School²⁶. Another evidence of this circumstance is the practice of therapeutic ob-

stinacy, professional attitude that is common in the majority of ICUs in the country because of the finite condition of human life¹⁴. The length of ICU hospitalization was higher in the group submitted to LLS (19,5 days) when compared to the group submitted to CPR (7,8 days).

Meanwhile, considering the high death rates in the first 24 hours of admission (22%), situation that was described in other studies conducted in Brazil^{14,16}, it seems like this fact is a result of the delay in forwarding the children to treatment in tertiary hospitals, what reflects the unsatisfactory flow of the system of reference/counterreference in force in the country or, in other words, ratify the inexistence of effective communication among the basic units of health and other instances of the public health network²⁷. Furthermore, the fact that 32 from the 33 patients that died in the first 24 hours had been submitted to CPR maneuvers when admitted seems to indicate that professionals performed the procedure because they don't know the diagnosis of the underlying illness from that children and considered them recoverable.

The finding that in none of the cases the healthcare team decided to interrupt life support procedures that had been previously installed is in disagreement with the data from international literature where this practice is more common, with 27% in France²², 32% is the U.S.²¹ and 34% in Canada²⁸. Brazilian law doesn't make a distinction between passive and active euthanasia, nor makes reference to euthanasia, dysthanasia or orthothanasia. However, the item III from Article 5 of the Federal Constitution establishes that *no one shall be submitted to torture or degraded or inhuman treatment*²⁷.

What probably justifies the attitude of intensive care doctors in opt for not interrupt any life support procedures previously installed is the fear of answer in court by omission of help, as provided in Articles 13 and 135 from the Penal Code. They would rather maintain the mechanisms of artificial life support, even knowing they would be incurring in therapeutic obstinacy. Fear of legal issues, therefore, influence the decision-making related to the attitude towards the the end-of-life. As a result, many doctors embrace the maximum certainty strategy, in other words, keep the full treatment to all patients without consider their clinic condition, until the imminent death imposes itself as final¹⁹.

The Federal Medicine Council (FCM), aware of this difficulty, inserted in the Medical Code of Ethics (MCE) the fundamental principle XXII and the

sole paragraph from Article 41 that establishes: *In cases on incurable and terminal illnesses, the doctor should offer all palliative care available without engaging in useless and obstinate therapeutic and diagnostic actions, always taking into consideration the express will of the patient or, if this is impossible, of his legal representative*²⁹. It's important to remember that one of the most respected Brazilian constitutionalists, Luís Roberto Barroso, talking about the CFM Resolution 1.805/06, that discuss the issue of orthothanasia, said that: *There's no doubt, nor ethical or legal, in the light of social values and constitutional principles, that (...) the resolution is an adequate interpretation of the Constitution*³⁰.

The Resolution 1.805/06 had its effectiveness suspended in a ruling from the Federal Judge Luis Roberto Demo, from October 2007, that accepted the Civil Action in the Public Interest filed by the Federal Prosecution Office. Later, on February 2011, the judge reviewed his decision and revoked the injunction that he granted before: *after thinking about the issue I'm convinced that the Resolution [from CFM] that regulates the possibility of the doctor to limit or interrupt procedures and treatments that extend the life of a terminal patient is not against the legal system*³¹. This finally allowed us to recognize the legality of the resolution, now definitely and nationally, since it was issued by a federal judge.

Patients that die in pediatric ICUs normally display associate comorbidity³², which was also observed in this study, where 64% from the deaths occurred in patients recognized as carriers of previous chronic diseases. However, there was no significant association between the existence of the chronic disease and the decisions of limitation of life support, data that coincides with the described by Lagos in 2005¹⁶. It's curious to register that, although the limitation of life support consists in an issue surrounded by many doubts, because of its moral complexity, there's no record, in any of the medical records studied, of any type of consultation with the Ethics Committee of the University Hospital, fact that is also reported by Mink in 1992⁷.

The participation of patients' relatives in the process of therapeutic decision-making about attitudes towards the end-of-life of its dependents was inexpressive. In only seven cases (5%) there was a written report of some sort of dialogue with relatives, but only six of them were cases of brain death, condition in which the family must be asked to decide about a possible organs donation. In the other cases, it's believed that relatives only received a verbal warning about the severity of illness and the bad

prognosis of the child's disease, there's no written record about any type of deliberative process that involved them. This data differ from the presented by foreign authors, and in some services family participation reaches 100%³³⁻³⁵.

Meanwhile, studies conducted in other countries from Latin America show similar results, what seems to demonstrate that the medical paternalism still part of the reality of our continent^{8,14,19,26}. This unsatisfactory reality can only be explained by the maintenance of the asymmetrical relationship between doctor and relatives because of the tremendous distance of education that exists between them. However, it's necessary to highlight that nothing justifies this attitude of disrespect towards humble people that, in the distorted view of professionals, would be incapable of making decisions about the life of their own children^{14,36}.

Unfortunately, in the majority of pediatric ICUs of the country persist this attitude of detachment of the doctor regarding the patient's relatives³⁷, although there are some encouraging initiatives of some professionals that, through an honest and welcoming dialogue, deliberate with the parents of the children with terminal illness about the possibility of the interruption of disproportionate procedures and the suggestion of non-resurrection orders, with the purpose of saving the children from the extended agony and unnecessary suffering.

Final Considerations

We must conclude that the study represents a small sample of the great complexity observed in the medical assistance offered in pediatric ICUs. We're aware of the limitation of information collected in only one of so many university hospitals in the country. Therefore, we reiterate that the retrospective studies conducted through the analyses of hospital deaths present limitation in the evaluation of results, especially when they are related to the end-of-life in ICU. Thus, our findings indicate the need of new studies about this issue. However, it seems essential to introduce them, even as a way of stimulating new researches.

The results now exposed are consistent with the information collected in other national studies, what just emphasizes the necessity of health professionals to make sure that pediatric patients with terminal illness receive from them the best of their technical and human capacities. Finally, the findings that seem more significant to us from this study are:

1. The difficulty to interrupt life support measures in the patients studied seems to reflect some insecurity from the professionals in making decisions that involve complex moral conflicts, especially because the fear of being convicted for omission of help;
2. There was no record of interruption of life support measures, even considering patients with terminal illnesses;
3. The majority of patients studied were submitted to the CPR procedure in the moments leading to death;
4. There are no evidences, in the medical records, of the participation of patients' relatives in any medical decision-making procedures;
5. In the sample studied there's no record of consultation with the Ethics Committee of the hospital.

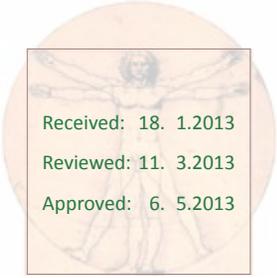
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Authors' participation

Daniela Grignani Linhares collected and analyzed the data and developed the study to the Master Degree in Sciences of Health from the State University of Londrina (UEL); José Eduardo de Siqueira guided the study, participating in the data analysis and final text of this article; Isolde T.S. Previdelli did the statistical analysis, contributing in the analysis .



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