

End of life in pediatric intensive care units

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Abstract

This article analyzes end-of-life procedures in Brazilian pediatric intensive care units. This is an observational, retrospective, multicenter study, including children who died between January and December 2017. During the period, 149 deaths occurred, of which 54 were selected. We found that 83.3% of patients had a base illness, being septic shock the main cause of death (38.9%). Life support limitations were described in 46.3% of the medical records, and a do-not-resuscitate order for 37% of the patients; however, 74.1% were not resuscitated. The practice of not resuscitating patients with a reserved prognosis and better care in the last 48 hours of life have become more common in recent years. However, there are still excessive use of invasive procedures, mechanical ventilation, and vasoactive drugs in the last hours of life.

Keywords: Hospice care. Death. Intensive care units, pediatric. Palliative care. Child care. Critical care.

Resumo

Fim de vida em unidades de terapia intensiva pediátrica

Este artigo analisa as condutas de fim de vida em unidades de terapia intensiva pediátrica brasileiras. Trata-se de estudo observacional, retrospectivo, multicêntrico, incluindo crianças que faleceram entre janeiro e dezembro de 2017. Durante o período ocorreram 149 óbitos, dos quais 54 foram selecionados. Constatou-se que 83,3% dos pacientes apresentavam alguma doença de base, com choque séptico como principal causa de óbito (38,9%). Limitações de suporte de vida foram descritas em 46,3% dos prontuários, e ordem de não reanimar em 37%; porém, 74,1% dos pacientes deixaram de ser reanimados. A prática de não reanimar pacientes com prognóstico reservado tem se disseminado, e aponta-se para melhores cuidados nas últimas 48 horas de vida. No entanto, ainda se verifica uso excessivo de procedimentos invasivos, ventilação mecânica e drogas vasoativas nas horas derradeiras.

Palavras-chave: Cuidados paliativos na terminalidade da vida. Morte. Unidades de terapia intensiva pediátrica. Cuidados paliativos. Cuidado da criança. Cuidados críticos.

Resumen

Final de la vida en unidades de cuidados intensivos pediátricos

El objetivo de este artículo es analizar las conductas al final de la vida en unidades de cuidados intensivos pediátricos brasileños. Este es un estudio observacional, retrospectivo, multicéntrico, que incluye a niños que murieron entre enero y diciembre de 2017. Durante el período, ocurrieron 149 muertes, de las cuales 54 fueron seleccionadas. Se encontró que el 83,3% de los pacientes tenían alguna enfermedad de base, con shock séptico como la principal causa de muerte (38,9%). Las limitaciones de soporte vital se describieron en el 46,3% de los registros médicos, y el orden de no resucitar en el 37%; sin embargo, no se resucitaron el 74,1% de los pacientes. La práctica de no resucitar a pacientes con mal pronóstico es cada vez más frecuente, y ya se pueden observar mejoras en la atención en las últimas 48 horas de vida. Sin embargo, todavía hay un uso excesivo de procedimientos invasivos, ventilación mecánica y drogas vasoactivas en las últimas horas.

Palabras clave: Cuidados paliativos al final de la vida. Muerte. Unidades de cuidado intensivo pediátrico. Cuidados paliativos. Cuidado del niño. Cuidados críticos.

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*Death should be like this: a sky that gradually grew dark
and we didn't even know
it was the end...¹*

The end of life, the only and absolute certainty of all beings, is also perhaps the most mysterious event of life, comparable only to the origins of the Universe. At the same time, humanity and its historical tools, such as science and medicine, tries to combat it at all costs, or perhaps to discover ways to overcome it. In the case of children, the issue is even more controversial. If it is hard to accept the frugality of existence when facing the death of the elderly – who, completing their “life cycle,” end in the ultimate experience –, it is even worse when it occurs in childhood.

Historically, the care for the sick has evolved and changed. Doctors replaced priests, shamans, and family members, and established the goal of healing at the hospital, making it a therapeutic space *par excellence*. According to Martin², with the insertion and development of the medical sciences in hospitals, medicine and nursing became a professional field. Thus, health practices gained technical and scientific competence but ended up leaving aside the humanitarian dimension of care³.

In this sense, humanity has supposedly advanced in the preservation of children's lives. The mortality rate in pediatric intensive care units (PICU), thanks to countless health measures and technical and scientific advances, which include the expressive increase in the number of beds^{4,5}, has fallen about five times, being currently between 3% and 10%⁵, although it may reach 20% in the first 24 hours of hospitalization as a result of acute, serious, and irreversible diseases⁶. The high number of deaths caused by acute diseases can result from “mysthanasia” – death due to lack of access or the precariousness of health services and poor socioeconomic conditions, as in many Brazilian cities.

The dichotomous burden that arises automatically when increasing patient survival in the PICU has been widely discussed. A large portion of these children had their lives prolonged by medical efforts and, being considered terminally ill, needed palliative care that would guarantee their dignity at the end of their life⁷. Therefore, life support limitation (LSL) has become a common practice in patients admitted to PICU^{6,7}. This limitation is characterized by the interruption or not providing interventions, as they only delay the process of dying, aggravating the suffering of patients and their families.

The incidence of LSL in the world ranges from 30% to 79%⁵, being more accepted in the Northern hemisphere⁸. In Latin America, some efforts to study this practice have been made, demonstrating its progressive dissemination, although the practice is still mostly limited to the do-not-resuscitate order (DNR). In other words, terminally ill children have been receiving support – even if it is unnecessary – until they suffer a cardiorespiratory arrest and are not resuscitated^{4-6,9,10}.

Given this context, to characterize the end-of-life care generally offered to patients, we observed the support provided to the terminally ill in their last 48 hours before death, in three PICU of a reference hospital complex (in assistance and teaching), considering more than a decade of the most comprehensive studies on the subject.

Materials and method

This is an observational, retrospective, multicenter study that includes medical records of children who died between January and December 2017 in three Brazilian PICU belonging to reference teaching hospitals linked to the University of São Paulo: the University Hospital, Children's Institute of Hospital das Clínicas, and Children's Cancer Institute. All PICUs had similar healthcare infrastructure: one to three intensive care pediatricians on duty, pediatric intensive care residents, and pediatric residents.

The procedures are defined by two daily medical visits, in the morning and at the end of the day. The first is a secondary PICU and mostly receives healthy patients, while the others receive patients with trauma or who have complex diseases (cardiovascular and oncological illness, or those that require liver, kidney, or bone marrow transplantation).

The participants were selected by the analysis of medical records of each PICU between January 1st and December 31, 2017, and patients who died in that period were also included in the study, even if their admission was before the period considered for the research. Patients with brain death and those who died within the first 24 hours of hospitalization were excluded.

From the medical records, we collected the following data: demographic data (age, gender, length of stay in the PICU); death (cause, number of organ failures in the last 48 hours of life, complete cardiopulmonary resuscitation maneuvers – defined by chest compressions, ventilation, use of the defibrillator, and adrenaline –, and LSL recorded in

medical records); clinical conduct in the last 48 hours of life (dosage of vasoactive drugs, information on mechanical ventilation, analgesic dosage and sedation). The data was collected according to the conduct of medical visits on the day of death and on the previous two days separately (24 and 48 hours).

In this study, we considered invasive all procedures that overcome natural barriers and that may cause pain to the patient (for instance, central venous catheter, invasive blood pressure, orotracheal intubation, endoscopy, myelogram, etc.). The acronym VIS was used to indicate the vasoactive-inotropic score, calculated as follows (dosages): dopamine (mcg/kg/min) + dobutamine (mcg/kg/min) + 100×adrenaline (mcg/kg/min) + 10 × milrinone (mcg/kg/min) + 10,000 × vasopressin (units/kg/min) + 100 × noradrenaline (mcg/kg/min).

“Analgesia” is understood as the administration of weak and strong opioids, and “sedation” as benzodiazepines, propofol, and ketamine. Increased or decreased ventilation is characterized by changes in blood pressure parameters, or the fraction of inspired oxygen or respiratory rate. Continuous variables were expressed as means and irregular variables as medians. The study was approved by the research ethics committees of the three institutions involved and the informed consent form was not necessary in this case.

The Bioethics Center of the São Paulo Regional Council of Medicine (Cremesp) encouraged the project through a research grant to resident doctors in an institution located in that state, with a program accredited by the National Committee of Medical Residency established by Cremesp Resolution No 284/2016¹¹.

Results

We found 149 deaths registered between January and December 2017 in the three teaching hospitals participating in the study. In addition, we excluded 52 medical records from the study, as they referred to newborns or adult organ donors. Another 26 records were excluded since the patients did not die in the PICU, and finally 14 patients who died within the first 24 hours of admission and three others who died of brain death were excluded. Therefore, the study comprised a total of 54 pediatric patients.

The median age of patients was 38 months (3 years and 2 months). Biological sex had a homogeneous distribution, with 29 (53.7%) males

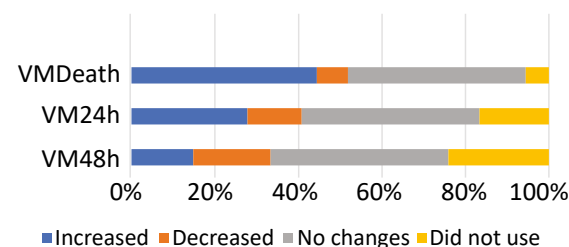
and 25 (46.3%) females. The length of hospital stay had a median of 12 days. Upon admission, only nine children (16.7%) were previously healthy, while 45 (83.3%) had some base illness. For the later, liver diseases (33.3%), oncological diseases (17.7%), and immunological diseases (8.8%) were the most prevalent. The most frequent causes of death were septic shock (38.9%), respiratory failure (14.8%), hypovolemic shock (13%), and hemophagocytic syndrome (9.3%).

Of the 54 children, 17 (31.5%) were considered as terminally ill at a given time of hospitalization. During the last 48 hours of life, from the six systems considered (respiratory, cardiovascular, neurological, renal, hematological, and hepatic), the average of dysfunctional systems was four. The medical records of 25 children (46.3%) described some form of life support limitation, and 20 (37%) had a do-not-resuscitate order. However, 40 (74.1%) of the 54 children were not resuscitated.

Regarding care in the last 48 hours of life, 28 (51.9%) invasive procedures were performed, with a median of one per patient. Twenty-five (46.3%) children received some form of dialysis in this period. At the time of death, 92.5% of the total of patients were on invasive mechanical ventilation in the assist-control mode, only two were on non-invasive ventilation, and two did not use any form of mechanical ventilation.

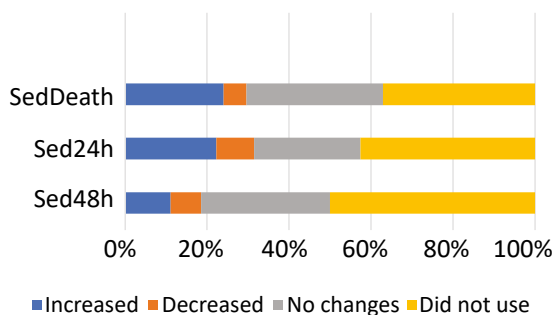
The VIS had a median of one during the last 48 hours of life, rising to 7.5 on the day before death, and reaching 52 on the day of death. Regarding the use of antibiotics, the spectrum of treatment of about 80% of patients remained without changes throughout the analyzed period, being expanded in only 3% of patients in their last days of life. The medical teams' behavior regarding the use of mechanical ventilation, analgesia, and sedation are summarized in Figures 1, 2 and 3.

Figure 1. Use of mechanical ventilation



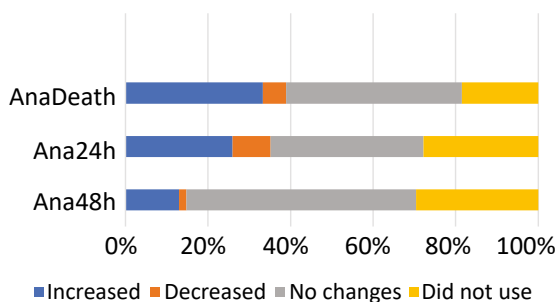
VMDeath: use of mechanical ventilation on the day of death;
 MV24h: use of mechanical ventilation the day before death;
 MV48h: use of mechanical ventilation two days before death.

Figure 2. Use of sedation



SedDeath: use of sedation on the day of death; Sed24h: use of sedation the day before death; Sed48h: use of sedation two days before death.

Figure 3. Use of analgesia



AnaDeath: use of analgesia on the day of death; Ana24h: use of analgesia the day before death; Ana48h: use of analgesia two days before death.

Discussion

The results of this study indicate that in the last decade there has been little progress in the citations of LSL in medical records. A literature review carried out in 2007 by Lago and collaborators⁶ pointed out LSL rates in Latin America, especially in Brazil, of 40%, the DNR order being the most frequent practice. A decade later, this study found an incidence of 46.3%, with the DNR order remaining the main measure. However, we noted that in daily life LSL has advanced considerably.

Although the DNR order was described in 37% of medical records, 74.1% of children did not receive any resuscitation maneuver in the first cardiorespiratory arrest. When analyzing the LSL descriptions, the terms “comfort measures,” “prioritize comfort,” and “support measures” are very common. However, few medical records describe LSL as “end-of-life planning,” objectifying and naming such measures by the expressions: “do

not increase VAD,” “increase sedoanalgesia,” “do not perform painful procedures,” “do not take tests”.

Therefore, it is an ethical controversy, and we can infer that in the last ten years the medical team’s awareness has increased concerning the need to limit futile treatments, but at the same time legal or moral fears still prevent the registration of LSL planning. When the decision for LSL is registered on the medical record, family members usually have only a passive role in the decision making. The phrases “we informed the seriousness of the case” and “we explained the progression of the disease” were very common in the medical records, and family members rarely appeared as protagonists of decisions⁶.

Concerning the practices used in the last 48 hours of life, we found the medical teams were less aggressive with the use of antibiotic therapy, considering 80% of the children had a constant dosage or it was suspended. Regarding analgesia, there was an increase in 12.9% of patients two days before death and 33% on the day of death; only 18% of children had no analgesia at the final moment.

Apparently, there is less motivation for sedation, since about 75% of patients continued to take the same dosage, or the dosage decreased, or they were not sedated on the day of death. In a positive way, perhaps this conduct aims to preserve the patient’s communication with family members or follow the good practice of never performing sedation without analgesia. But it can also reflect the team’s fear, so culturally ingrained, of accelerating the dying process.

Regarding the use of mechanical ventilation and VAD, the results were not encouraging. We verified a progressive increase in mechanical ventilation parameters in the last 48 hours of life. On the day of death, almost half of the children had the parameters increased, and only 3% did not use any form of mechanical ventilation. Concerning the use of VAD, VIS increased by 750% from the antepenultimate to the penultimate day of life, and by 5,200% when comparing two days before death with the moment of death. This measure was reduced in only four (13%) of the 29 children who used it the day before death, and the VAD of only two children (7%) were removed. In contrast, VAD was introduced in 10 (40%) of the 25 children who did not use it the day before death.

The overall incidence of invasive procedures was 51.9%, with a median of one procedure per patient. In this study, among the 25 children

with any LSL described in their medical records, 10 (40%) still underwent at least two of these procedures, and 11 (44%) were dialyzed in the last 48 hours of life. Therefore, even when describing measures in the medical records to reduce pain and suffering, the staffs continue to adopt practices that are often futile, as indicated by the national and international literature^{4-7,12,13}.

Final considerations

This study, carried out about a decade after similar reviews in Brazilian PICUs, reveals a wide advance in end-of-life care. The practice of not resuscitating patients with a reserved prognosis has spread, and a better care has been provided in the last 48 hours of life. However, invasive procedures, mechanical ventilation, and VAD are still overused in the last hours.

We also note a need to better record end-of-life plans in the medical records of patients in the final stages. Such descriptions show that patients and families are still not the protagonists in these cases, and that an individual-centered medicine has not been widely adopted.

According to the manual published by the National Academy of Palliative Care, it is *important to remember the role of the family. In the pediatric practice, parents legally represent their children in all aspects of clinical and therapeutic decisions, in ethical and social decisions. Ethical and legal issues must be respected. When the patient is a child, it is not always easy to talk about freedom of choice, respect for patients' wishes, and their right to honest and quality communication*¹⁴.

Therefore, we must keep working on the daily care of patients and families in this delicate moment of life, to better analyze, comprehend and improve healthcare.

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