



End-of-life care in pediatrics: much more than a fight against entropy

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I must have called in sick the day they taught about death in Medical School. However, even if my wise masters had dedicated every class on that cold day in June of 1995 when I had acute tonsillitis to convoluted discussions about death, their efforts would have been clearly insufficient. I might not have known about death then, but I knew about statistics and probabilities. Chances were that the classes on that day had the same orientation of every other class of the many days of the 6 years during which I became a physician: how to diagnose the various illnesses and how to treat them to restore health and preserve life.

I understand that death is not a frequent entity in many specialties, even within Pediatrics. I know that some colleagues practice their art and science for entire careers without necessarily encountering the death of those who entrusted them their lives or the lives of their loved ones. To them, the many classes on diagnosis, treatment and health restoration, I am certain, created exceptional physicians. Pediatric Intensive Care, however, is not one of those specialties. The cruel reality is that: 1) death is a frequent occurrence in pediatric intensive care units (PICUs) and 2) the death of a child defies the natural order of life where parents die before their children, adding several orders of magnitude to the pain of the final separation.

The choice for Pediatric Intensive Care came to me during the first year of Pediatric Residency while caring for the son of a colleague hours before watching his body be consumed by fulminant septic shock. I decided then to dedicate the next 7 years of my medical career to gain the knowledge needed to defeat this and other pathologies ubiquitous to the PICU; an infantile fantasy of cheating death. However, what I learned along those and subsequent

years from masters of ethics and of physician-patient relationship such as Enio Rotta, Ashok Sarnaik, David Steinhorn and Bradley Fuhrman was that Pediatric Intensive Care only serves its purpose when it is not used as a weapon in a blind fight against entropy. I learned that death is part of life and not diametrically opposed to it. I learned that while 96% of the approximately 1,400 patients admitted

annually to our multidisciplinary PICU continue their life trajectory, approximately 4% die in spite of, and some due to, my efforts. I learned that life and death are fluid processes – they might be bright and dark at the extremes, but are connected by a broad area of penumbra. I learned that in this penumbra resides the limit that, when

crossed, makes the difference between doing something for the patient and doing something to the patient; when instead of prolonging life one prolongs death. Knowing exactly where this limit is for each patient is the Holy Grail of Pediatric Intensive Care.

The discomfort in speaking of death is evident in the PICU environment. While frequently present, the “D” word is rarely vocalized. I observe with empathy when my residents and colleagues fruitlessly attempt to avoid it, using euphemisms such as “my patient will pass away,” as if this charade of words could attenuate the harsh reality: “my patient will die.” If we can barely speak of death, understanding it will be even further out of reach. The search for this understanding begins when we examine our practices regarding death and the circumstances that surround it. In this issue of the *Jornal de Pediatria*, two groups have advanced our knowledge in this area.

Lago et al.¹ and Tonelli et al.² conducted cross-sectional observational studies in tertiary PICUs in Brazil. The first¹ retrospectively explored patterns of life support limitation (LSL) in 155 deaths of children in three tertiary hospitals in Porto Alegre. The other² prospectively described the behavior preceding the death of 112 children admitted to the Federal University of Minas Gerais Hospital. Despite dealing with different samples and conditions, both studies report similar figures for the prevalence of some form of LSL, 36.1%¹ and

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52.8%,² respectively. These prevalences are in line with that reported by Carvalho et al.³ (40.9%), but still well below the prevalence observed by Garros et al.⁴ in a Canadian PICU where after limitation or withdrawal of life support 72.7% of patients either died or evolved to brain death. The low prevalence of cardio-pulmonary resuscitation in the Canadian study⁴ (27.2%) reflects a more natural attitude towards death in the Northern hemisphere. However, significant progress in this area has been observed in Brazil, considering that in 1998 the prevalence of LSL in one of the PICUs included in the Lago et al.¹ study was only 6%.⁵

Some of the data in the studies of Lago et al.¹ and Tonelli et al.² are a matter of concern. Only 3.2% of patients studied by Lago et al.¹ and none of those studied by Tonelli et al.² died after withdrawal of life support, with strong preference being given to the more passive limitation of support, despite it being widely accepted that no significant ethical differences exist between the two.⁶ The low parental participation in the decision-making process (9.2%¹ and 20.8%²) and the scarce parental bedside presence at the time of death (14.8%¹) were alarming. The lack of documentation of the decision-making process of LSL¹ in 30% of cases, made worse by the occurrence of seven cases² of discrepancies between the medical record and the actual facts (report of reanimation attempt when in reality one did not occur) and the two cases of “simulated” reanimation¹ were unacceptable. I applaud the objectivity and clarity with which the authors report these difficult findings, since it is only through this characterization that the understanding needed to end these abominable practices will be achieved.

The exclusion of parents and patient from the decision-making process, the reluctance to limit or withdraw life-sustaining therapies and the false reporting of events on the medical record have complex and multifactorial origins, involving cultural, ethical, legal and religious aspects that are beyond the scope of this text but that have been elegantly articulated by Kipper et al.⁷ Some specific issues, however, deserve comment. Many health care professionals invoke ethical principles to defend their practices against limitation or withdrawal of life-sustaining therapies. However, it is the opinion of this editorialist that such rationale is a fallacy.

Medical ethics is ruled by the basic principles of autonomy, beneficence and non-maleficence. Respecting autonomy means allowing patients to exercise their own wishes, provided that they are competent and that the autonomy of others is not infringed. Whenever the medical team makes a unilateral decision while excluding the patient and the parents or legal guardians, a flagrant violation of autonomy occurs. The principles of beneficence and non-maleficence rule that the objective of a physician’s actions should be the well-being of the patient, and that some harm is acceptable when the net result is beneficial (e.g. side effects during chemotherapy). It becomes impossible to justify beneficence and non-maleficence by performing CPR, advanced support therapies such as mechanical ventilation, dialysis, ECMO or many of the other modalities indicated in potentially reversible

situations in a terminal patient. The same rationale should be employed when considering Article 57 of the Code of Medical Ethics,⁸ which affirms that a physician is prohibited from “failing to utilize all available means within reach to diagnose and treat in favor of the patient.” While potentially ambiguous, this article defends beneficence and non-maleficence; in this context, “in favor of the patient” should translate into what best serves the interest of the patient, and not into a determination that obligates the indiscriminate deployment of futile therapies. Lacking any ambiguity, however, is the less often invoked but equally important Article 33 of the same Code,⁸ which rules that a physician is prohibited from taking responsibility for a medical act not performed by the physician or in which the physician did not effectively participate.” As such, falsely reporting reanimation procedures⁹ or end-of-life decisions is clearly unethical and immoral.

A frequent but equally flawed explanation for the reluctance in limiting or withdrawing life support and withholding resuscitation in Brazil is the fear of being accused of the crime of omission, as ruled by Article 135 of the Penal Code,¹⁰ according to which it is a crime of omission to “fail to provide assistance whenever possible without incurring personal risk...”. It is the opinion of this editorialist that, if the patients and guardian so wish and the medical team agree, the withdrawal of life-sustaining treatment accompanied by an order not to resuscitate does not constitute failure to provide assistance, but rather the precise type of assistance indicated for that particular patient.

Pediatric Intensive Care is a developing specialty that has witnessed incredible technological advances over the past few years. As a result of such advances, one can now easily cross the limit between prolonging life in favor of prolonging death. As such, the circumstances involving the death of children in PICUs must be absolutely clear. Medical entities at the federal and state levels must position themselves to clarify ambiguities and support health care professionals. Hospitals must incorporate clear “Do Not Attempt Resuscitation” orders (preferred over “Do Not Resuscitate,” as this suggests that resuscitation is always possible), according to which what will and will not be done for any given patient is determined *a priori*. Units must incorporate a code sheet where a neutral party documents, in real time, all the facts, occurrences and therapies used during reanimation, in addition to the attending physician’s note. Units must also have a systematic review process of all reanimations, deaths and morbidities, including quality indicators and documentation. The doors to the unit must be open to family members so as to encourage dialogue, and so that they can exercise the right to participate in rounds and in the informed decision-making process, and, when desired, the right to be present at the time of death. No one should die without having the opportunity of being comforted by a loved one. Advances in end-of-life care in PICUs depend on the complete understanding of the circumstances surrounding death. Lago et al.¹ and Tonelli et al.² have taken an important step in the right direction.

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Toxocariasis and asthma: a relevant association

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The article by Figueiredo et al.,¹ published in the current issue of *Jornal de Pediatria*, provides important information about clinical and epidemiological investigation into toxocariasis in the pediatric population. The study analyzes the association of *Toxocara canis* infection with some variables, such as asthma, cough, recurrent pneumonia, hepatomegaly, and eosinophilia, among others, in infants and children treated at public outpatient clinics of Pediatrics, Immunology and Pneumology. This cross-sectional study was motivated by the diverse clinical manifestations of toxocariasis and its association with asthma. Of 208 patients, 106 were asthmatic. Association measures were established between variables and positive serology for *Toxocara canis*, considering a $p = 0.05$ as statistically significant. All of 114 who were seropositive (54.8%) for *Toxocara canis* received thiabendazole. In 86.6% of cases, infection was subclinical; and 13.4% concerned the visceral larva migrans syndrome (VLMS).

Toxocariasis is a parasitic infection. It was described by Beaver et al.² in 1952 as VLMS, after being detected in three children with pulmonary disorders, hepatomegaly, and

eosinophilia. The larva of *Toxocara canis* was detected in one of the liver biopsies.

There are three clinical forms of toxocariasis:³ a) VLMS – characterized by frequent fever, pulmonary disorders, hepatomegaly, eosinophilia, among others; b) ocular toxocariasis – described by Wilder⁴ in 1950, based on enucleated eyes, with suspected retinoblastoma. Ocular

toxocariasis is characterized by eye pain and hyperemia, reduced visual acuity, strabismus, and leukocoria, with the following types of ophthalmic disorders: retinal granuloma (located on the posterior pole or in the peripheral retina), endophthalmitis, uveitis, keratitis, vitreous abscess and optical

neuritis; c) covert toxocariasis – less frequently diagnosed form whose major symptoms include abdominal pain, hepatomegaly, occasional eosinophilia, and lower limb pain.

Of the causative agents of VLMS³ in human beings, *Toxocara canis* is the agent most frequently found in the tissues of these patients. Puppies younger than 10 weeks of life are the typical reservoir of *T. canis*, as they are infected transplacentally. Human beings, especially children, become infected when, after contact with contaminated soil, mainly in parks and gardens, they ingest infective eggs (geophagy, onychophagy, by placing their fingers in their mouths).

Jacob et al.,⁵ analyzing 40 cases of VLMS, obtained the following clinical findings: pallor (70%), abnormal pulmonary auscultation (60%), hepatomegaly (50%), splenomegaly (20%), fever and adenomegaly (15%). In 13 cases, referral

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