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EDITORIAL

When the story is too short☆

Cuando el relato es demasiado corto

Francisco Jose Cambra[a,b,*], **Sara Bobillo-Perez**[a,c]

[a] *Unidad de Cuidados Intensivos Pediátricos, Hospital Sant Joan de Déu, Universitat de Barcelona, Barcelona, Spain*
[b] *Institut Borja de Bioètica, Barcelona, Spain*
[c] *Grupo de investigación de la disfunción inmunológica y respiratoria del paciente crítico pediátrico, Institut de Recerca Hospital Sant Joan de Déu, Barcelona, Spain*

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Will I experience the death of a child during my professional career? It is possible that many of our young paediatricians occasionally pose this transcendental question to themselves.

Child mortality, a clear indicator of child heath, has decreased significantly through the years, reducing the number of exposures of paediatricians to the end-of-life process in their patients. Unfortunately, this decrease has not been uniform, and there are still parts of the world where mortality rates remain intolerably high.

The study published by Luc Onambele et al.[1] made a detailed analysis of child mortality and its changing trends in the European Union over a period of more than 20 years, and is a source of comfort in that it confirms its consistent decline. Among the reasons that may explain this decreasing trend, the article highlights the role of the development of vaccination. Children with complete vaccination are at lower risk of death than unvaccinated children. This proven fact, which reinforces the need of maintaining and improving vaccination programmes, clashes with movements that campaign against vaccination and place children at risk by leaving them defenceless.

As paediatricians, it is our role to protect the health of our children, and we should ask ourselves composedly whether limits should be placed on the autonomy of parents when their decisions go against the best interests of their children.[2]

The so-called welfare state, which has improved the economic and social conditions of the general population through a substantial investment in public health, may have contributed significantly to the decrease in child mortality. Maintaining this system requires a rational use of health care resources. In paediatrics, new treatments emerge day to day, some with exorbitant costs. Determining their indications and whether they should be funded by the state requires a deep reflection involving paediatric specialists in different fields.

Assessments of mortality take into account the number of deaths in infants aged less than 1 year resulting from congenital malformations. The implementation of prenatal screening programmes for detection of congenital malformations may have been associated with an increase in the number of voluntary terminations of pregnancy, which would have reduced the number of infants aged less than 1 year at

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[*] Corresponding author.
E-mail address: fjcambra@sjdhospitalbarcelona.org (F.J. Cambra).

risk of early death, thus artificially inflating the estimated decrease in child mortality.

The excellent article published by Agra et al.[3] analyses the modes of death in children deceased in 8 Spanish paediatric intensive care units (PICUs) between 2011 and 2017, a project that was launched by the Ethics Group of the Sociedad Española de Cuidados Intensivos Pediátricos (SECIP). The sample included 337 deaths, corresponding to 2.2% of children admitted to the PICUs. Fifty percent of the deaths followed limitation of life-sustaining treatment (LoLST), a term classically used in the context of intensive care that in Spain is also known as ''adaptation of the therapeutic effort'', an expression that may be more illustrative to some. The study found a decrease in mortality compared to previous studies, a profoundly encouraging fact that can be attributed to improvements in intensive care. Other contributing factors may be that more children are dying in hospital inpatient wards and in their homes thanks to the important work developed by palliative care services in Spain.

Limitation of life-sustaining treatment is the most frequent cause of death, either by withholding initiation of support measures or withdrawing those already initiated. This decision is usually based on 2 criteria: the uselessness of potentially available treatments and the significant reduction in quality of life in case of survival. The futility of treatment is a subject that should be brought up by professionals, who would explain to the parents the advisability of withholding or withdrawing such treatments.[4] The assessment of quality of life is directly affected by the values of the patient or the parents, compounding the complexity of decision making. Maintaining treatments or initiating additional treatments with the sole purpose of preserving life when the only end that is achieved is to prolong the process of dying or survival with such poor quality of life that it may be considered that death would have been preferable is simply a manifestation of therapeutic obstinacy. Limitation of life-sustaining treatment is meant to prevent this obstinacy and ought to be perceived as a good clinical practice that prevents unnecessary pain and suffering. The fact that this is the mode of death in half of the children deceased in intensive care units is an indicator of the understanding of medical ethics of intensivists and other specialists involved in the care of these children in Spain, the correct management of the range of available treatments and the level-headed and accurate perception of disease and its prognosis by the patients or, in most paediatric cases, their parents.

Paradoxically, there is also evidence of an increasing frequency of situations where parents demand the initiation of therapeutic measures that are considered clearly futile by clinicians and the implementation of which, in response to family, pressure from the generates what has been aptly termed *moral distress*,[5] as clinicians consider these interventions detrimental to their patients and find themselves acting against their moral convictions. It is these situations, too, that, as we mentioned above, should lead to consideration of the extent to which the autonomy of parents could or should be challenged, and their wishes opposed.[2]

Organ transplantation plays a decisive role in the decrease of mortality and the improvement in quality of life. The demand amply exceeds supply, and in light of this situation, or controlled donation after circulatory death (Maastricht category III) is currently developing in the paediatric clinical field in Spain. Patients that die following a decision to limit support could become donors following this protocol. For parents, it may be a source of comfort to know that their child is contributing to the wellbeing of another child and another family after death. Paediatricians that are exposed to these situations can assess this possibility and present it, along with the transplant coordinator, to the parents.

In response to the question that opened this article, most paediatricians will not have to face the death of a child or help a family cope with this devastating experience.

In the opinion of Agra et al., the decreased exposure to death of paediatricians may hinder their ability to approach this process appropriately.[3]

Our society is in pervasive denial of death, which is perceived as something distant and frightening, both attitudes that are reaffirmed in the event of a child's death. The death of a child violently confronts us with a phenomenon that deviates from the natural course of things. The growth of the child, the unfolding of a healthy and fulfilling life are severed, leaving family members in shock, and frequently paediatricians, too. It is difficult to come to terms with such a brief trajectory, a life narrative that concludes so shortly after starting, and from this perspective, one can understand the extreme measures that may be attempted to prevent the death of a child, which underscores the crucial importance of understanding LoLST.

It is unquestionable that paediatric palliative care specialists, intensivists and oncologists, to cite a few specialities, face the death of their patients more frequently. However, even if child mortality is decreasing, all paediatricians and residents in paediatrics must be aware of the need to be qualified to correctly manage residents in paediatrics the end of life in a child.

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