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Facing up to limits: a lesson from the Charlie Gard case

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Dear Editor,

The Charlie Gard case [1] generated immense media interest, but more importantly has bequeathed a valuable lesson to doctors and nurses around the world.

Firstly, it reminds us that doctors should never propose any therapy or drug if they have not examined the patient and are not familiar with all the medical documents. This essential factor cannot be overlooked, no matter how expert the doctor wanting to participate in the patient's care may be. This becomes even more relevant when discussing new treatments to be considered for compassionate use in a particular patient, before the drug has undergone the rigorous preclinical and clinical testing required by law.

Violating this principle can lead to confusion and creates false expectations in patients and families, but, importantly, also in others suffering from the same disease. In medicine, insufficient professional rigour and accountability can engender unnecessary pain and suffering for those concerned.

Secondly, the case has reminded us that medicine, and specifically, high quality clinical care, must respect the confidentiality of the patient and the family, which means maintaining long periods of silence even in the face of international media clamour for information.

Thirdly, palliative care represents the best treatment strategy in cases of incurable illness in children.

As paediatric intensivists, anaesthesiologists and paediatricians involved in the care of terminally ill children, we would like to express our appreciation of how Great Ormond Street Hospital staff approached difficult decisions and utilized appropriate communication channels. The paediatric ICU staff gave prominence to the delicate and silent job of taking care of critically ill children [2]; they pointed out that it could be a difficult and painful task requiring them to attempt always to make the right (or rather, less wrong) choice, including the possibility of being misunderstood and targeted with sometimes ill-informed criticism.

Paediatric health care is practised with the goal of promoting the best interests of the child. In some cases, on a thorough assessment of benefits and costs to the child, deciding to forgo life-sustaining medical treatment is the only ethically justifiable and appropriate option. Many scientific societies have supported this opinion. The Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care recommends that "*the availability of a diagnostic or therapeutic tool does not in itself impose the obligation to use it. The use of a diagnostic or therapeutic tool must comply with a criterion of proportionality, even in intensive care. (...) The decision to limit, withdraw or withhold life-sustaining treatments considered disproportionate, thus allowing the evolution of the illness to take its natural course towards death (...) represents a clinically and ethically correct choice*" [3]. The very recent guidelines of American Academy of Pediatrics fully support this

approach and they also state: "*It may be ethically supportable to forgo life sustaining medical treatment without family agreement in rare circumstances of extreme burden of treatment with no benefit to the patient beyond postponement of death*" [4].

Medicine that does not recognise the existence of limits has little chance of being good medicine.

Key words

End of life decisions, withdrawing of life supports, withholding of life supports, Paediatric Intensive Care Unit, clinical ethics, palliative care.

Conflicts of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

References

1. Wilkinson D, Savulescu J. After Charlie Gard: ethically ensuring access to innovative treatment. Lancet 2017;390:540-542. doi: 10.1016/S0140-6736(17)32125-6
2. It was our agonising job as Charlie Gard's care team to say: enough. The Guardian (4 August 2017) <https://www.theguardian.com/uk-news/commentisfree/2017/aug/04/it-was-our-agonising-job-as-charlie-gard-care-team-to-say-enough> Accessed 1 September 2017
3. Giannini A, Messeri A, Aprile A, Casalone C, Jankovic M, Scarani R, Viafora C. End-of-life decisions in pediatric intensive care. Recommendations of the Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care (SARNePI). Paediatr Anaesth 2008;18:1089-95. doi: 10.1111/j.1460-9592.2008.02777.x
4. Weise KL, Okun AL, Carter BS, Christian CW; Committee on Bioethics, Section on Hospice and Palliative Medicine, Committee on Child Abuse and Neglect. Guidance on forgoing life-sustaining medical treatment. 2017;140(3). pii: e20171905. doi: 10.1542/peds.2017-1905