

Beyond resources: declining parental requests for futile treatment

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The sad and difficult case of Charlie Gard,¹ is the latest in a series of court cases in the UK when parents and doctors have disagreed about medical treatment for a child. Doctors regard the treatment as “futile” or “potentially inappropriate”.² Parents, in contrast, want treatment to continue. In the current case, the judge rejected Charlie’s parents’ request for him to travel to the US for an experimental medical treatment.³ He ruled that life-sustaining treatment could be withdrawn, and Charlie allowed to die.

When doctors and the courts consider cases like this one, they often focus exclusively on best interests.⁴ In some cases, however, it is uncertain whether or not treatment would be in the interests of the patient. Indeed, there may be stronger and clearer arguments to limit treatment on the basis of finite and scarce medical resources.²

The different ethical reasons that justify a decision not to provide treatment might come together, or they might come apart (Figure 1).

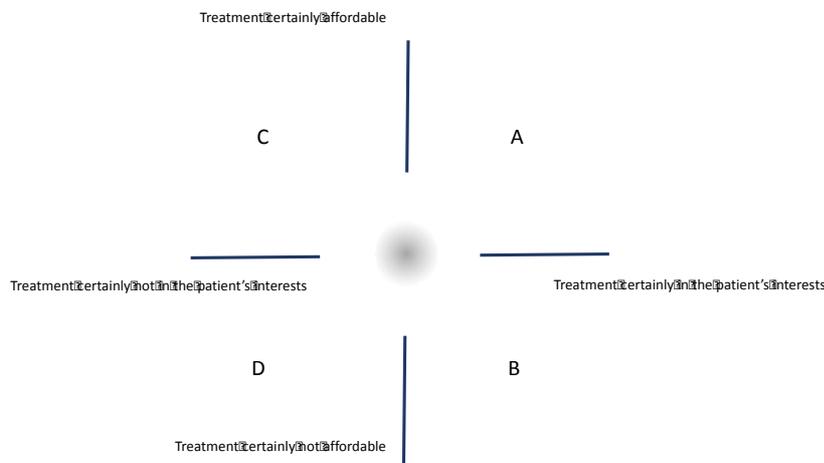


Figure: Reasons to limit treatment, best interests and resources.

If treatment would be both affordable and in the child’s interests (region A in the figure), it should unquestionably be provided. If it is neither affordable, nor in the child’s interests (D), treatment should not be started or should be stopped. Where there is uncertainty about the benefits and costs of treatment (the central ‘grey zone’ in the graph), parents’ views are crucial. But sometimes the picture is more mixed. Perhaps treatment is in the interests of the patient, but unaffordable within a public health system (B)? In the Charlie Gard case, parents had crowdsourced funding to enable him to be taken to the US for treatment. That would mean that the resource issue is not relevant. Perhaps for him treatment would be in region C, affordable, but contrary to interests?

One way of thinking about what would be in someone’s best interests is to imagine a set of scales. On right side of the scales are the reasons in favour of a course of action, on the left are the reasons against. If it were a question of weighing a small chance of a positive outcome against an empty scale, the balance would be tipped in favour of treatment, even if the chance (or magnitude) of benefit were tiny.

But there **are** often significant negatives in the balance. Being kept alive in intensive care is not pleasant. Although we do our best to provide pain relief, sedation, care and comfort to

gravely ill children and babies, that ability is finite and imperfect. Children on long-term ventilation often appear uncomfortable at least part of the time. They have frequent needles and invasive procedures. They may be distressed and unable to communicate the source of their distress.

Julian Savulescu argues below [\[link\]](#) that the small chance (perhaps 1 in 10,000) of benefit would outweigh the negatives of treatment in intensive care. However, a shift in perspective casts that into doubt. Charlie Gard's condition is extremely rare, but imagine that there were a sudden epidemic of mitochondrial DNA depletion syndrome affecting 1000s of newborns. Would it really be ethical to artificially ventilate for months 9999 infants (who will experience discomfort and suffering and then die), in order to achieve some measure of improvement in 1 infant? Setting aside any question about resources, it seems wrong to harm 9999 infants to benefit one child. That implies that this chance of recovery is too slim to make treatment plausibly in the current child's interests.

The reason why these decisions come to the court at all is because parents do not have an absolute right to make medical decisions for their children. Parents are given broad discretion about how to raise their children, how to feed them, how to educate them, whether or not to immunise them. Parents will not always make the best choices, but for the most part the state will not interfere or intervene. However, where parents' decisions run a significant risk of causing serious harm, their decisions must be challenged, if necessary in a court.⁵

When it comes to experimental treatment, there can be different reasonable views among health professionals about how to weigh up the chance of benefit against the burdens of the treatment. In the face of such disagreement, the decision properly belongs to the parents.⁶ Assuming the treatment is affordable, (and the parents want it), it should be provided. However, where no professionals think that the experimental treatment is worth pursuing, parents' request for treatment should not be granted. In the Charlie Gard case, one expert in the US was prepared to provide treatment. However, the expert admitted that the treatment had never been tried in a child with established encephalopathy and that benefit was "unlikely"; the judge clearly felt that this did not represent a reasonable option.³

These decisions about life-sustaining treatment for critically ill children are fraught and difficult for all involved. Parents are, rightly, at the heart of the decisions that are made in intensive care. Their views about treatment are important, and their wishes are usually followed. However, there are limits. Sadly, reluctantly, doctors and judges do sometimes conclude and are justified in concluding that slim chances of life are not always better than dying. Providing comfort, avoiding painful and unhelpful medical treatments, supporting the child and family for their remaining time: sometimes that is the best that we can do, and the only ethical course.

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