

Ethical dilemma: what have we learned from the Charlie Gard case

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Introduction

Charles Matthew William Gard (Charlie Gard) was born in 2016 in the United Kingdom with ribonucleotide reductase regulatory TP53 inducible subunit M2B–related mitochondrial DNA depletion syndrome, encephalomyopathic form with renal tubulopathy, which is a rare genetic disease¹ that causes progressive brain damage and muscle failure. There is no treatment and death usually occurs in infancy.² Charlie Gard's case caused a dispute between the medical team and the parents because they disagreed on whether an experimental treatment was in Charlie's best interests. This commentary discusses the potential bioethical issues around this case, such as crowdfunding and the need for complex legal proceedings, and presents some recommendations for future cases.

The legal case

Charlie's parents wanted to attempt nucleoside replacement therapy but the doctors at Great Ormond Street Hospital believed it would be ineffective. The hospital asked the High Court in February 2017 to reverse the parents' decision, which it did. The parents filed appeals with the Court of Appeal, the Supreme Court, and finally the European Court of Human Rights.³ The court ultimately ruled that palliative care was in Charlie's best interests. Charlie was admitted to a hospice on 27 July 2017 after mechanical ventilation was removed. He died the next day.

The challenges of a best interests decision

Applying bioethical principles to paediatrics can be challenging because some cases may lack the capacity for analytical thinking and decision-making, particularly for newborns who have no ability to understand the point of view of bioethical principles. In the case of Charlie Gard, the medical practitioners at Great Ormond Street Hospital warned that innovative therapies could harm Charlie's health and exacerbate his suffering, but Charlie lacked the ability to comprehend the situation. Lago et al⁴ believe that

procedures or treatment decisions that lengthen the lives of critically ill patients should be based only on medical discussions because the professionals are aware of the benefits and potential adverse effects. Mr Justice James Holman emphasised that parental opinions were not determinative but simply personal preferences.⁵ The subjective opinions of the parents had nothing to do with what was objectively in the child's best interests. The underlying ethical point of view is not about the medical practitioner or the parents whether having control or responsibility for the decisions regarding the child's care, but rather what is ultimately in child's best interests.

Complicated legal procedures may aggravate clinical conditions

Charlie Gard's case involved complicated legal procedures that continued for nearly 6 months. The final decision of the court seemed inevitable, but there may have been room for improvement, especially as most children with mitochondrial DNA depletion syndrome die before the age of 4 months.⁶ One solution might have been to set up a time-limited trial of treatment with distinct termination criteria, such as no improvement or adverse effects, especially given the unpredictable efficacy of experimental treatment⁷ and Charlie's deteriorating health. This approach may help to alleviate the suffering of dying children and provide a middle ground for parents who disagree with the child's medical attendants. Furthermore, children could receive experimental treatment under the most ideal physical conditions to obtain the greatest success rate.

Mitigation more preferred than court decisions

Charlie Gard's case demonstrates that the judicialisation of medical decisions can lead to unsatisfactory outcomes. Moreover, the court has an overriding legal power, potentially resulting in an irreversible decision that all must abide by. Instead, better communication and compassion between health practitioners and parents would enable all to reach an agreement without the need for legal

intervention. Waldman and Frader⁸ suggest that, in the Gard case, his parents might not have had professional knowledge of nucleoside therapy and lacked the skills required to weigh the risks, benefits, and potential efficacy. Medical professionals should explore and establish clear care goals with families as early as possible to mitigate disagreements and conflicts. By doing so, the family feels included in the treatment and management and that their opinions are respected. This approach may reduce the psychological burden on the family, even when treatment must be terminated.

Crowdfunding may intensify healthcare inequality

Charlie's parents used crowdfunding to help pay for the experimental therapy. However, this would not have covered the resources needed for Charlie's treatment.⁹ Tertiary and academic medical centres that perform research and provide specialist services such as nucleoside treatment depend on long-term and continuing investment. It is therefore misleading to assume that medical crowdfunding may fully compensate for the treatment it intends to support.

Conversely, the crowdfunding process transfers community-funded health services to individual beneficiaries because it allows unique patient groups to benefit from special treatment, which aggravates medical inequalities. Normally, patients and families who already have broad social networks have more success in raising funds.¹⁰ Additionally, donors are usually people in the same socio-economic class as the patients. Hence, crowdfunding is based on external factors, such as perceived social values, instead of conventional indicators such as medical needs. This does not mean that crowdfunding is unethical, but it is important to recognise that there would still be a considerable cost to the public healthcare system where such funding is used to pay for treatment.

Remaining professional in unusual cases

Healthcare professionals must always be aware of and follow the laws and professional standards that govern their professional registration. Physicians should practise ethically and be honest in all professional interactions.¹¹ The Nuremberg Code emphasises that the implementation of clinical trials must be based on the results of prior animal experiments and the outcomes of similar studies, ensuring the expected outcomes of the trial are valid.¹² Additionally, adequate facilities should be provided to minimise the potential risk of injury, disability, or even death to the patients. Therapies should be administered in such a way that no unnecessary physical or mental suffering or injury results.

Medical staff of different cultural backgrounds may have major ethical differences¹³ that could cause disagreements or even conflicts among colleagues. With globalisation, these kinds of exchanges, which transcend regional cultural differences, will occur more frequently. The key is to abandon one's own opinions and instead focus on the interests of the patient. It is for this reason that, in the end, all parties agreed to palliative care because Charlie's quality of life was so poor that he would no longer be able to potentially benefit from the therapy.

Conclusion

This essay explored the complexity of best interests decisions and the influences of court involvement in the case of Charlie Gard. Some recommendations, including setting up a time-limited treatment trial with distinct termination criteria and strengthening medical mediation, may be helpful in achieving consensus about a patient's best interests while avoiding complicated legal procedures.

Author contributions

Both authors contributed to the concept or design of the study, acquisition, analysis, and interpretation of the data, drafting of the manuscript, and critical revision of the manuscript for important intellectual content. Both authors had full access to the data, contributed to the study, approved the final version for publication, and take responsibility for its accuracy and integrity.

Conflicts of interest

Both authors have disclosed no conflicts of interest.

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