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PEDIATRIC PALLIATIVE CARE (KS HOEHN, SECTION EDITOR)

# Charlie Gard: How Did Things Go Wrong?

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**Abstract**

**Purpose of Review** We examine the discussions generated to date by the Charlie Gard case, as well as the events of the case itself, in order to examine lessons for providers dealing with similar situations in the future.

**Recent Findings** Publications regarding the Gard case are relatively few and focus primarily on the ethical and legal issues that arise when involving the court system in complex medical decision-making and potential limits to parental authority. Some publications have also addressed the subject of experimental therapies, especially from the perspective of potential harms, suffering, and cost.

**Summary** We suggest early introduction of palliative care and careful attention to communication might reduce conflict and improve satisfaction for all involved parties. Likewise, we suggest limiting court system to truly extraordinary circumstances; all efforts should be made to avoid legal action and to honor and respect parental authority.

**Keywords** Palliative care · Parental authority · Best interest · Harm · Communication

## Introduction

The tragic death of Charlie Gard bears measured reexamination and an attempt to analyze the responses it generated, in order to extract lessons applicable to similar future cases. As others have noted, advances in genetic diagnostics and therapeutic innovations will likely generate many more complex clinical situations such as this [1•].

In reviewing this case, we want to remember we cannot know the private, likely nuanced, conversations that occurred between the Yates/Gard family and various members of Charlie's clinical team. No doubt these discussions included prognostic uncertainty and the burdens of life-supporting treatment. However, we do not know details of the language clinicians used, the questions the parents asked, or whether the Great Ormond Street Hospital (GOSH) staff achieved a meaningful parent-clinician alliance. With that in mind, we hope to step back some and identify critical elements in the decision-making such that a different, less contentious outcome might have been reached.

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## History

First, we present a brief review of Charlie's story. He was born in London in August 2016. By October, he was being cared for at GOSH and was diagnosed with a form of mitochondrial DNA depletion syndrome, an extremely rare neurological and muscle disorder resulting from genetic mutations inherited from both parents. There are no treatments for this condition known to slow or ameliorate predictable degeneration. His condition deteriorated rapidly, requiring mechanical ventilation in the intensive care unit (ventilation was via endotracheal intubation; the question of tracheostomy placement arose in the midst of the conflict over nucleoside therapy, starting in January 2017, and tracheostomy was in fact never performed). With no realistic hope for cure and no proven interventions, GOSH clinicians, including an internationally known expert in mitochondrial disorders, recommended refocusing Charlie's care on comfort measures and discontinuing life-prolonging therapies. Charlie's family, understandably distraught, initiated their own search for possible interventions and identified a neurologist in New York whose work on related mitochondrial disorders might apply to Charlie. They

contacted Dr. Michael Hirano at Columbia University who suggested that experimental therapy he was developing could possibly help. The treatment involved administration of basic building blocks of DNA, called nucleosides, which might provide a "work-around" and bypass the nonfunctional enzyme causing Charlie's genetic disease. Dr. Hirano acknowledged that of the 17 patients he had treated, none had exactly the same genetic condition as Charlie. In fact, all of the 18 other children who had received this therapy had a different, generally less severe form of the condition (a TK2 mutation as opposed to the RRM2B mutation that Charlie had). Specifics of those other cases, including clinical status at time of treatment, have not been made publically available. In May, Hirano suggested in a letter that "In the best-case scenario, Charlie's condition would stabilize, improve partially or continue to improve with long-term therapy." (https://www.nytimes.com/2017/07/07/world/europe/uk-charlie-gard-us-doctor.html) In response, Charlie's parents raised more than $1.3 million US to pay for a trip to New York and treatment there. They asked that Charlie be transported to New York City. GOSH doctors felt that the transfer would not further Charlie's interests and referred the matter to the British courts. Subsequently, three levels of courts in England and then the European Court of Human Rights ruled that it would not be in Charlie's best interest to be moved for the experimental therapy and that life-prolonging therapies should be stopped. As Charlie's story unfolded, it garnered a fair amount of interest in both scientific and popular outlets. Individuals as prominent as Pope Francis and President Trump offered opinions. In mid-July, on further review of Charlie's status, Dr. Hirano determined that Charlie's condition had deteriorated so much that no therapy would help. Charlie's parents then asked that he be taken to their home to die. The medical team also refused this request, ostensibly based on a concern that the equipment such as the ventilator necessary to continue life-prolonging support would not physically fit into their home. Charlie was moved to an in-patient hospice where clinicians stopped life-prolonging measures and he died on July 28, 2017, just before his first birthday.

## Issues Raised by Charlie Gard's Care

### Communication and Trust

Perhaps the most important principle encompassing such a story involves relationships and the fundamental communication between patients (in Charlie's case, the parents) and clinicians. In the context of a poorly understood condition, though one with a clearly poor prognosis, decision-making was surely emotional and complex. This requires clear, honest conveyance of information by the medical team and careful, active listening with ongoing exploration of hopes, expectations, and goals of care. Reporting about Charlie's case suggests a breakdown in trust and communication with the development of entrenched positions, leading clinicians to turn to the legal system. No one should feel surprised, in the age of the internet, that, after hearing that the doctors would offer no new treatment, the parents searched for alternatives on their own, learning in January of Hirano's research. It is not clear how much the N.Y.-based neurologist communicated directly with the family and if the primary team in London participated in any mutual discussions including the parents and Hirano. If the GOSH clinicians recognized time as an issue, they might have sought rapid approval to use Hirano's intervention in early 2017 and done so in London. The GOSH clinicians might also have used language, at least in the court filings [2], less fraught with subjective determinations, such as "futile," "harm," and "suffering." Charlie's parents may have felt these terms communicated the team's lack of respect for them or even implied that they were not acting in his best interest (or, worse, that they acted only out of self-interest), rather than acknowledging the parents' love of and hope for Charlie. One wonders if earlier palliative care or clinical ethics consultation could have prevented or repaired troubled relationships involving the parents, the GOSH team, and Dr. Hirano in New York. In addition, we worry that media involvement, including social media discussion, distorted communication and inflamed any discord between Charlie's parents and the staff at GOSH. In the face of a great deal of publicity, maintaining necessary intimate and delicate discussions about the goals of care becomes particularly problematic.

Other examples of troubling language appear repeatedly in popular media, academic discussions, and court rulings regarding Charlie's case. The most upsetting is the persistence of a false dichotomy between continued life support and palliative care. Palliative care, rightly conceived and executed, involves treatments aimed at optimizing quality of life, including maximizing symptom control and psychosocial/decision-making support for patients and families facing life-threatening conditions. The use of palliative care should not depend on any particular, and often flawed, prediction of when life will end. Clinicians, administrators, policy makers, and courts must abandon this false distinction between providing palliative care and all other facets of good clinical care and embrace a more holistic approach that encompasses palliative care as part of the approach to caring for any child with a life-limiting illness.

### Assessment of Therapies

Charlie's case highlights the difficulties of assessing interventions with no proven track record and, in turn, the pitfalls of communicating scientific and clinical uncertainty to families and patients. As noted, Hirano suggested nucleosides *might*

stabilize Charlie's condition or even improve it somewhat. Clinicians usually appreciate ambiguities and subtleties that accompany clinical innovation; parents without a medical background, especially those experiencing the emotional distress of their child's critical, life-threatening illness, usually do not have the tools to appreciate such unknowns. Charlie's parents needed open, honest, and probably repeated conversations with their London team and Hirano in New York to understand and come to grips with what nucleoside administration might or might not accomplish.

Moreover, we imagine Charlie's parents knew that other infants at GOSH and across the U.K., and elsewhere, receive continuing life support (mechanical ventilation, medications of unproven effectiveness) without clinicians claiming the provided care harms the patients or involves futility. Some babies with poor prognoses from damaged lungs and severe neurological injury (from bleeding or periods of insufficient oxygen delivery to the brain) have long-term intensive care without clinicians turning to the legal system for permission to stop treatment and allow death. One would be hard pressed to fault Charlie's parents for being confused or even angry about apparent contradictions and lack of fairness regarding Charlie's care compared to the care of other infants in dire circumstances.

As Lantos recently noted, advances in genetic diagnosis will likely get to the point where "every patient and disease will be genetically distinct" [1•]. In Charlie's case, the GOSH team and the courts relied on the differences between Charlie's mitochondrial disorder and those for whom Dr. Hirano has been developing treatment. However, we do not now know how to decide that genetic subtypes of rare conditions are similar or different enough that the condition will or will not respond to a single drug. While genetic homogeneity may make for the "cleanest" results in formal clinical trials, we do apply less stringent rules for clinical use in desperate situations. As others have pointed out, Charlie's medical team and the courts could have done so in this case with little harm to the National Health Service or clinical pride, even if just as a time-limited trial [3].

## Involvement of the Court System

Moving to the courts likely destroyed remaining vestiges of trust between the family and the medical staff, shifting decision-making from the appropriate medical discussions of goals of care and family-centered values to legal consideration of the best interest of the child. Others have pointed out that the concept of best interest as elaborated in pediatrics poses problems, both because it is hard to define and it fails to acknowledge legitimate interests of others, especially patients' other family members [4••]. Best interest determinations are inherently subjective and heavily dependent on the particular values of the decision-maker. In Charlie Gard's case, the best interest judgment seems to have hinged on whether he was suffering and whether Hirano's therapy offered a real possibility of benefit. Alternatively, one could have framed decisions around the risks of harm from continued life support and receipt of nucleosides [4••]. Interestingly, the courts agreed that nucleosides per se were unlikely to cause harm, though transporting Charlie to New York in his fragile state involved real risks. Again, it remains unclear why the treatment could not have been expeditiously approved for use in London [5••]. As to the harm of continued treatment, the available public information is inconclusive regarding whether Charlie, with his substantial encephalopathy, experienced pain or suffering from his continued life support. Pediatric intensive care clinicians surely know how to use analgesics and sedatives to minimize stress and discomfort from intubation, mechanical ventilation, and associated treatment, but the question of suffering, which involves a subjective component, appears to have been a point of contention among providers.

Readers should understand that the British legal system for disputed medical treatment of children differs from the approach used in the U.S.A. In the U.K., while parents have responsibilities for caring for their children, the courts have overriding authority for determining best interest when parents and clinicians clash. In these cases, U.K. courts must decide, albeit on the basis of testimony from parents and experts. Thus, when families and clinicians reach an impasse, UK courts must step in and decide [6]. This contrasts with a rather more discretionary approach to court involvement in the U.S.A. In any case, court involvement raises questions about the limits of parental rights. Even in Texas, where clinicians have perhaps the broadest latitude to impose medical judgment about continuing so-called nonbeneficial or futile care, parents still have a time-limited opportunity to find alternative sources of care for the patient, including different hospitals and clinicians. This also appears to have been the situation with the much-publicized Jahi McMath case here in the U.S.A., where, after clinicians determined brain death, the family sought legal action to prevent removal of physiologic support of her organs. Despite ongoing legal battles, the hospital ultimately agreed to transfer the body to the coroner's office and from there, the family took her, still receiving mechanical ventilation and support of other body systems, to another state that allows dissent from a determination of death based on neurological criteria. In effect, the outcome in the McMath case preserved parental authority over and against overwhelming medical opinions. In Charlie Gard's case, in which no one claimed Charlie had already died, the courts precluded such an option, disregarding parental wishes. Given fundamentally different value perspectives affecting Charlie's care, especially about whether his continued life harmed him, court imposition of a solution may not represent the morally most satisfactory solution [5••]. Overriding

parental judgements about sustaining life, in the absence of clear-cut harm, requires extreme caution and special attention to the establishment of precedents that erode parental rights.

### Following the Money

Some of the discussion of the Charlie Gard case has focused on the expense of keeping Charlie alive in the face of almost certain, rapidly approaching death (most mortality in children with mitochondrial disorders results from neurologic and respiratory deterioration, leading to pneumonia and/or sepsis) [7]. While we could not argue that his treatment was inexpensive, one needs to keep two facts in mind. First, at least in the U.S.A., medical care of children represents between 10 and 15% of all health care spending. The single most expensive expenditure for pediatric care in the U.S.A. involves hospital care of normal newborn babies. The overall cost of pediatric intensive care of the sort Charlie received is relatively small, compared to many other aspects of health care spending. Second, while justice arguments, such as the amount of time, effort, and money that went into caring for Charlie have importance, especially in systems such as that of the U.K. with fixed budgets for hospitals or regions, allocating care should depend upon broad social policy agreement about what is or is not "worth it." Bedside rationing risks, invocation of idiosyncratic and biased decisions should be avoided in all but the direst of circumstances, such as combat or devastating epidemics.

### Timeline

Though caution and careful deliberation have their place in medical management, the prolonged timeline of the Charlie Gard's story bears mention. The primary factor seems to have been drawn out court proceedings with nobody involved feeling satisfied with the outcome. Charlie's parents were not allowed to take him to the U.S.A. for experimental therapy. The GOSH clinicians, including doctors, nurses, and therapists, worried about his pain and suffering but had to maintain him on life support. This case, and others like it, call out for a pathway for expedited proceedings [5••]. It would seem to make much more sense to decide early on to try experimental therapy or offer compelling reasons not to do so. This should also, as noted earlier, serve as a reminder of the benefits of early involvement of palliative care services, who may be best suited to help ensure that pain and any perceived suffering are adequately addressed. Moreover, assessing suffering, much less pain, in children with severe encephalopathies seriously challenges currently available clinical tools.

## Conclusions

As we noted, it is impossible to know the details of the many interactions that constitute Charlie Gard's story. Most of us have participated in-patient care experiences in which, despite best efforts, misunderstandings and miscommunications have occurred and relationships soured. Charlie's saga should remind us of the critical role communication and establishment of trust play in delivering medical care, especially when navigating difficult, uncertain circumstances for children with rare conditions. Early and ongoing exploration of goals of care with the family may help to avoid or at least mitigate some conflicts, as the clearer a family's goals, the more likely their decision-making will make sense to all involved. In Charlie Gard's case, we only know effective communication ceased. Perhaps more open, honest, and realistic evaluation of potential therapies, including nucleosides, might have averted conflict. Parents faced with the unthinkable very understandably search for any option that might offer hope, though parents rarely have the tools to evaluate the reasonableness of available options. Clinicians need to recognize that parents may not appreciate the subtleties and ambiguities associated with innovations that medical personnel know and accept. As noted, with rapid progress in genetic diagnoses and the concomitant development of new interventions, situations similar to Charlie Gard's are likely to become more common.

### Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

## References

Papers of particular interest, published recently, have been highlighted as:
- • Of importance
- •• Of major importance

1.• Lantos J. The tragic case of Charlie Gard. JAMA Ped. 2017;171:935–6. **An important notation of the implications of expanding genetic knowledge and testing.**
2. High Court of Justice Family Division. Great Ormond Street Hospital v. Constance Yates and Chris Gard [2017] EWHC 972 (FAM). Case No. FD17P00103.
3. Wilkinson D, Savulescu J. Hard lessons: learning from the Charlie Gard case. J Med Ethics. 2017;0:1–5.
4.•• Shah S, Rosenberg A, Diekema D. Charlie Gard and the limits of best interest. JAMA Peds. 2017;171:937–8. **Provides a reminder about the inherent problems with typical notions of best interest in pediatrics.**

5.•• Wilkinson D, Savulescu J. After Charlie Gard: ethically ensuring access to innovative treatment. Lancet. 2017;390:540–2. **A cogent summary of an alternative approach to the use of unproven interventions.**

6. Caplan A, McBride Folkers K. Charlie Gard and the limits of parental authority. Hastings Cent Rep. 2017;5:15–6.
7. Truog R. The United Kingdom sets limits on experimental treatments. JAMA. 2017;318:1001–2.