



EDITORIALS

Restoring balance to “best interests” disputes in children

The court of public opinion is surely the worst possible place for ethically complex decisions

Dominic Wilkinson *professor of medical ethics*¹ *consultant neonatologist*¹

¹Oxford Uehiro Centre for Practical Ethics, faculty of philosophy, University of Oxford, UK; ²John Radcliffe Hospital, Oxford, UK

Difficult and ethically challenging discussions about life prolonging treatment for a seriously ill child usually take place in quiet side rooms adjacent to medical wards. Sometimes, when parents and doctors have struggled to reach agreement, these discussions involve external mediation or take place in ethics committees. Rarely, unresolved dispute moves that discussion to a courtroom. In the recent Charlie Gard case, however, these discussions have taken place in public, on a wide global stage.

The Gard case raises ethical questions that are important to debate publicly.¹ Yet much of the discussion about the case has been distinctly unbalanced. Commentators, politicians, and some supporters of the family attacked the hospital, the doctors, and the health system. Overseas medical and scientific experts, politicians, and religious leaders ventured opinions and offered treatment, apparently without knowledge of the full clinical circumstances.^{2,3}

On the other side, the hospital and health professionals involved didn't feel able to defend themselves in public out of concern for the confidentiality of the child and family and to protect staff of the hospital. Independent experts have been reluctant to comment because of the lack of important medical details.⁴

The High Court is not the best place to make medical decisions—though sometimes regrettably that is the only available option. But the court of public opinion is surely the worst possible place for ethically complex decisions. The intense media attention and debate about Charlie Gard led to abuse and threats to staff and to Charlie's family.⁵ Unrealistic or unfounded claims may also have provided false hope and contributed to the protracted legal battle.

How can we achieve greater balance in future? One option would be to maintain the anonymity of any child at the heart of a dispute over treatment. This is the norm for cases in the Family Court.⁶ While anonymity might be better for the child, it can also limit parents' options, making it harder to fundraise for treatment and potentially harder to identify supportive expert opinion. It also conflicts with freedom of the press and raises concerns about lack of transparency in decision making.⁷

Another possible solution would be to allow (or require) medical professionals to make public the evidence on which they are basing their decisions. That would enormously increase transparency, and help ensure that any wider discussion is based on relevant and verifiable facts. It would, however, breach the child's confidentiality.

A way forward

Firstly, most discussions and decisions about treatment will continue to occur in private, though it would be valuable to gather and publish data on the frequency of conflicts and their outcome. One study of end-of-life decisions in newborn intensive care in the Netherlands, reported disagreement between professionals and the family in 12% of cases. Agreement was reached eventually in all, without resorting to the courts.⁸ A better understanding of the epidemiology of conflict would help put cases like Charlie Gard into a broader context and identify better ways to resolve them.⁹

Secondly, where disagreements have reached the court, it is helpful (as already occurs in many cases in the UK) for legal judgments to be published.¹⁰ Publication facilitates understanding about the ethical and legal basis for decisions, and can help us anticipate how the court might approach future cases.

Thirdly, in most cases, health professionals should avoid disclosing patient medical details outside the doctor-patient relationship or the courtroom. However, where a court has allowed parents and children to be identified, and particularly if there is already public debate about a child's medical treatment, it may be in a child's best interests to make available some of the evidence and arguments underpinning professionals' decisions.

In the latter parts of the Gard case, Great Ormond Street Hospital elected to make publicly available their position statements to the court,³ presumably on this basis. This allowed a more realistic understanding of the medical considerations. It can also facilitate external scrutiny and help identify whether there are

alternative viewpoints within the profession nationally or internationally.

Finally, in reference to the controversial intervention of a doctor from the US, Justice Francis noted “It seems to me to be a remarkably simple proposition that if a doctor is to give evidence to this court about the prospect of effective treatment . . . that doctor should see the patient before the court can sensibly rely upon his evidence.”² His comments serve as a note of caution for the media and the wider community about relying on the opinion of professionals who have not accessed all the clinical details.

The public attention and debate around Charlie Gard hasn't been all bad. It has brought wider attention to the potential futility of medical treatment, to the suffering of families of children with life limiting illnesses, and to important ethical questions about the rights of sick children and the respective roles of parents and health professionals in protecting them. It has provided encouragement and support to Charlie Gard's family. Families who disagree with medical professionals can feel vulnerable, alone, and disempowered, and find it difficult to oppose the power of the medical establishment.

Sound ethical analysis depends on knowing more than just the scientific and medical facts. But without the facts, or with incorrect facts, there is a danger of jumping to incorrect and potentially harmful conclusions. It is in the interests of all children that cases like Charlie Gard's are accompanied by fair, accurate, and balanced discussion.

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