

Philosophical Medical Ethics: More Necessary Than Ever

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When we applied for the editorship of the JME seven years ago, we said that we considered the JME to be the most important journal in medicine. The most profound questions that health professionals face are not scientific or technical, but ethical. Our enormous scientific and medical progress already outstrips our capability (in personnel, time and physical resources) to provide treatment. Life can be prolonged at enormous cost, sometimes far beyond the point that the individual appears to be gaining a net benefit from that life. Science can tell us how to achieve something, but it can't tell us whether we should achieve that end—whether it is good. For that, we need ethics.

Ethics grows in importance as our technology creates new possibilities. Where there are no options, there are no ethical questions. However, once there are options, there arise pressing questions about whether to pursue them. (To reverse an old aphorism, “can” raises the question “ought we?”) We require values and principles to decide how to use medicine and science. During the last seven years, issues like the creation of brain organoids, human nonhuman chimeras, mitochondrial transfer, gene editing of embryos and *in vitro* gametogenesis have grown in prominence. These raise deep questions about moral status and how it should be determined, the limits of modification of the human, and what is good in life.

As Editors of the JME, we are proud of our small contribution to thinking about these challenges. We are grateful to the hard work of our Associate Editors and administrative staff. But there is still much more to do.

During our term as editors, we have published papers from diverse perspectives, on a wide range of topics. We have seen vigorous debate within the pages of the journal, and have often sought to deliberately encourage that debate by publishing contrasting viewpoints—for example, within our Feature Article and Authors meet Critics formats.

A new feature of the ethics landscape is the empowerment of patients through the internet. Exposure to different perspectives and to information about treatment options means that patients and families no longer necessarily accept the values and ethics of medical professionals. Debates about definitions of death that many thought had been settled three decades ago have been re-animated. In 2013, two years into our tenure at the journal, Californian teenager Jahi McMath was diagnosed as brain dead following a complication of a surgery for sleep apnoea. Four and a half years later, she continues to be maintained on a ventilator in her new home in New Jersey. The legal and ethical battles continue to rage over whether she has manifested any signs of neurological improvement over that time, and whether, even if she hasn't, her family's rejection of a brain death diagnosis should be accommodated.

For us, a quintessential example of the importance of ethics to medicine is the recent case of Charlie Gard, the subject of this final issue of the JME under our editorial team. The case, along with the similar dispute, this year, over treatment for Liverpool infant Alfie Evans, highlights both the potential global dimensions

of these ethical debates, and the urgent need for ethical analysis. These cases also, we suggest, indicate a way that ethical progress is possible.

Justice Francis delivered his initial judgement about medical treatment for Charlie Gard in April 2017. We were struck at the time by the profound epistemic and normative questions at the heart of the case. What was Charlie's experience of the world? How much, if at all, was he suffering? What was the chance that the experimental treatment that his parents sought would lead to improvement? How should we assess the benefits and harms of this proposed treatment against the alternative—certain death? Despite having shared views on many questions in medical ethics, we found ourselves divided on the decision. JS was critical of the court decision but DW, a practising neonatologist, felt that, based on the evidence, it was ethically justified. JS and DW debated the ethical questions in private, and in print,[1,2] and continued to do so as the court heard a series of appeals.[3]

The process of argument can often be helpful in understanding what is at stake in an ethical debate. In ancient philosophy, this process of reasoned dialogue between opposing speakers was referred to as a dialectic. The dialectical approach was seen by the ancients to be a key way of making progress in philosophy. As JS and DW discussed and debated the Gard case [4] they found a greater understanding of the opposing point of view, and were led to reflect on, reconsider, and sometimes temper their own views. While there were commentaries on the case by a number of eminent US bioethicists,[5-8] we think other medical journals should have done more to present views on both sides of this issue, even those that ran counter to the medical orthodoxy. In this issue, we have tried to represent both sides of the debate (compare Paris (page XX) and Gillon (page XX)).

One approach to medical ethics seeks to identify points of agreement and consensus. While that is important, our own view is that the Gard and Evans cases highlight how difficult it is to reach agreement on fundamental normative issues. But disagreement and debate have great value. Instead of bemoaning the failure to reach a common understanding on challenging questions, we came to accept that there can be a range of reasonable answers to these questions. In a forthcoming book, two of us use the Gard case to explore ways to make progress despite disagreement.[9]

We have also reflected on how difficult it is to comment on specific cases when the information available is incomplete. There are highly likely to be relevant features of Charlie's condition and of his case that are not in the public domain, that might make a difference to an assessment of the ethical issues. Moral relativism is false but ethics is highly context sensitive and dependent on the facts.

When professionals hear "ethics", they often think of the many bureaucratic, wasteful and unethical obstacles to life-saving and life-enhancing research and practice. But ethics is also liberating: about what we should do, as well as what we shouldn't do. We tried to show how ethics could be constructive, instead of

merely obstructive. We developed an ethical algorithm for dealing with requests for experimental treatment [10] and more recently an ethics procedure for dealing with conflicts around treatment after the Alfie Evans case [11]. Huxtable in this issue (page XXX) offers a similarly constructive proposal and we have tried to identify lessons to enable future practice [3].

The case of Charlie Gard raised the deepest ethical questions of what makes life worth living, how that should be determined, what risks are worth taking to achieve a life worth living, how limited resources should be allocated, paternalism, authoritarianism, how evidence should be interpreted, who should decide what happens to children, and how those decisions should be made. We hope the selection of articles in this issue demonstrates the variety of reasonable perspectives on this issue, and how medical ethics is more important than ever.

This is our last issue as editors. We are happy with how the Journal has progressed over the last seven years. We have striven to encourage dynamic debate through publishing Feature Articles and commentaries. We have tried to make the Journal a more attractive place to publish in-depth ethical analysis through the addition of the Extended Essay category. We have actively commissioned high-quality contributions on topics that we believe are especially important or especially neglected. We have introduced new review procedures to increase the speed and fairness of the decision-making process. We hope that we have succeeded in cultivating more rigorous, detailed and lively debate on the most important topics in medical ethics. But there have been many challenges, and there are many issues on which we have made less progress than we would have liked. Let us end by mentioning three.

First, we would like to have done better in bridging the gap from empirical research to normative arguments and recommendations. We received many submissions that reported empirical findings relevant to ethical debates, but made little effort to analyse their ethical implications, either remaining purely descriptive, or simply asserting without argument that the results support particular ethical conclusions. Though we often tried to correct this problem through requesting extensive revisions or commissioning commentaries, we were often not satisfied with the progress that we were able to make.

Second, the Journal remains less internationally representative than we would like. We have had disappointingly little success in attracting contributions from the developing world.

Third, we frequently struggled with the tension between ensuring that we did not censor controversial viewpoints—for example on topics such as abortion and euthanasia, disability, Chinese organ procurement practices, chronic fatigue syndrome, and circumcision—and protecting the Journal and its authors from unfair and harmful publicity. The development of the blogosphere and social media platforms like twitter has helped to bring bioethical scholarship to a wider audience, but it can also mean that academic articles trigger storms of outrage, sometimes including threats made to authors and the Journal editors. We developed an approach of proactively identifying articles likely to elicit

controversy and taking steps to mitigate this in advance, but without altering our decision on publication. However, this was not always an easy line to walk and we suspect that managing controversy will become an increasingly thorny issue for journal editors in medical ethics and other highly polarized fields. We hope that editors will stand firm in publishing controversial but well-argued viewpoints.

By the time this editorial is published, the JME will be in the hands of John McMillan and his team of Associate Editors. It's time for a fresh approach and an injection of new editorial ideas, and we're pleased to be able to pass on the journal to such a strong team. We wish John and the new committee all the best in their efforts to further develop the Journal, to cement its place as one of the very top venues for scholarship in medical ethics, to continue to challenge received ethical wisdom, and to provide the ethical arguments and analysis needed to ensure that science and medicine serve the common good.

References

1. Savulescu J. Is it in Charlie Gard's best interest to die? *Lancet* 2017;389(10082):1868-69. doi: 10.1016/S0140-6736(17)31204-7
2. Wilkinson D. Beyond resources: denying parental requests for futile treatment. *Lancet* 2017;389(10082):1866-67. doi: 10.1016/S0140-6736(17)31205-9
3. Wilkinson D, Savulescu J. Hard lessons: learning from the Charlie Gard case. *J Med Ethics* 2018;44(7): INSERT PAGE NUMBERS
4. Wilkinson D, Savulescu J. The ethics of treatment for Charlie Gard: resources for students/media. *Practical Ethics in The News*. <http://blog.practicaethics.ox.ac.uk/2017/07/the-ethics-of-treatment-for-charlie-gard-resources-for-studentsmedia/>. Accessed 4 June 2018.
5. Caplan A, Folkers KM. Charlie Gard and the Limits of Parental Authority. *Hastings Cent Rep* 2017;47(5):15-16. doi: 10.1002/hast.772
6. Lantos JD. The Tragic Case of Charlie Gard. *JAMA Pediatr* 2017;171(10):935-36. doi: 10.1001/jamapediatrics.2017.3079
7. Shah SK, Rosenberg AR, Diekema DS. Charlie Gard and the Limits of Best Interests. *JAMA Pediatr* 2017;171(10):937-38. doi: 10.1001/jamapediatrics.2017.3076
8. Truog RD. The United Kingdom Sets Limits on Experimental Treatments: The Case of Charlie Gard. *JAMA* 2017;318(11):1001-02. doi: 10.1001/jama.2017.10410
9. Wilkinson D, Savulescu J. Ethics, conflict and medical treatment for children: from disagreement to dissensus: Elsevier 2018.
10. Wilkinson D, Savulescu J. After Charlie Gard: ethically ensuring access to innovative Treatment). *Lancet* 2017; 390(10094):540-542
11. Wilkinson D, Savulescu J, Barclay S. Disagreement, mediation, arbitration - how to resolve disputes about medical treatment. *Lancet* 2018; 391: 2302-2305.

