The concise argument

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This post-holiday edition of the JME brings together a number of papers, covering a range of methodologies, surveys on public opinion, the application of developmental neuroscience, comparative risk/benefit questionnaires, scoping reviews and analysis of guidance and health policy, alongside what might be seen as more traditional medical ethics, analysing concepts and advancing arguments. This range of methodologies is suggestive of the kind of discipline that bioethics has become, and how a wealth of disciplinary and methodological perspectives is needed to address the numerous challenges that face modern health systems.

The Editors' Choice article by Derbyshire and Brockman¹ considers the contentious issue of fetal pain, and applies developmental neuroscience to the question of at what stage, if at all, a fetus can feel pain? The authors argue that new evidence suggests we cannot rule out that fetuses might experience pain before 24 weeks. The authors define pain as being 'a raw experience' and therefore, 'the ability to feel pain does not have to be premised on self-reflection, which prevents a rejection of fetal pain because the fetal experience is not equivalent to an adult human experience.'¹ Hence, for the authors, pain does not have to be equivalent to adult pain to matter morally. The authors have differing views on abortion and this provokes a thoughtful discussion, in terms of what are the implications of these, although tentative, conclusions on fetal pain for practical approaches to carrying out abortions. They conclude by exploring how abortions might be carried out in a more humane way, that is, using fetal analgesia, and what such a humane approach might look like in light of this new evidence.

In this month's feature article Brick and colleagues² report on a study that surveyed a sample of the UK population on their views on allowing disabled children to die. Their survey was prompted by a number of recent cases that went to court in the UK, such as Charlie Gard and Alfie Evans. Charlie Gard was born with mitochondrial DNA depletion syndrome, a rare genetic disorder that usually results in death in infancy. At 3 months he was admitted to hospital and placed on a ventilator. After he experienced seizures

the hospital wanted to withdraw treatment as they thought that it was no longer in his best interests. However, his parents wanted to continue ventilation and explore the possibility of further treatment in the form of an experimental treatment that was being developed in the US. After a protracted legal process, where all courts ruled in favour of withdrawing ventilation, and the experimental treatment was eventually deemed inappropriate, the parents finally agreed to the withdrawing of life-support and Charlie Gard died. The case prompted wide-spread media interest and debate, with many expressing opposition to the legal view that life-support should be removed. A particular bone of contention in this case was that the ruling went against the parents' wishes (which was why it had gone to court in the first place). Brick *et al* noted that there is little evidence on the public's views on what constitutes 'a life not worth living', when treatment should be withdrawn and the status of parents' decisions. In their survey, they found that, 'a majority of participants indicated that treatment should be continued indefinitely for a child if parents wished this. The only case where participants believed parental wishes may be overruled was the case where the child was completely unaware.' And that, 'Contrary to our hypothesis, public opinions were not markedly different to the legal outcomes.'²

This article has prompted a number of responses. Truog³ points out that in the US both legal and clinical decisions are made on the basis of the harm principle 'which holds that parental choices for their children should prevail unless their decisions subject the child to avoidable harm,' rather than best interests. Other responses debate methodological issues raised by this kind of 'descriptive' ethics research. Lemmon⁴ highlights the limitations with using surveys, as the cases have to be stripped of context and the 'real-time' nature of decision-making is lost. Nelson⁵ also notes that a lack of context in the cases can make it hard to interpret the results of Brick *et al*'s survey and explores the limits of the generalisability of such findings. Nelson suggests this as a note of caution to those thinking of applying these results to clinical practice, healthcare policy and law. Wightman *et al*⁶ highlight that the

lack of diversity in the survey sample, with 92% of participants reported as white, is a particular problem for this topic area, where minority views may differ significantly from those of the majority. The use of empirical research in bioethics has been increasing over the last 20 years and there have been a number of recent papers addressing methodological standards⁷ and how quality in empirical ethics might be assessed.⁸ The debates in this issue of the JME over how surveys can inform normative debate and how these types of finding could be used as the basis of public policy, contribute to this growing field of bioethical inquiry and suggest fruitful areas for further exploration.

Turning to research ethics, Watson *et al*'s⁹ paper addresses potential problems with applying standard research ethics frameworks to 'opportunistic' evaluations, evaluations of programmes initiated with the aim of improving services rather than generating knowledge. The researchers involved in these evaluations have no control or ownership of the programmes and therefore certain requirements as set out in guidance such as The Ottawa statement on the ethical design and conduct of cluster randomised trials, are not relevant to this form of research. Their central claim is that people can only be held morally responsible and hence accountable, 'for those aspects of a study over which they have control.'⁹ Current guidance does just that and puts an unfair burden on researchers. Further, the Ottawa statement requires that 'interventions be justified on grounds of equipoise, minimal harm, and so forth, which would rule out many potentially beneficial evaluations of programmes.'⁹ Therefore, they argue that requiring adherence to such guidelines and procedures could hinder the carrying out of important research and it is clearly in the public interest to encourage, rather than discourage, this type of evaluation. In response to this argument, Weijer *et al*¹⁰ take issue with Watson *et al*'s claims on a number of grounds, a key one of which is how they define the key characteristics of opportunistic evaluations. Watson *et al* portray opportunistic evaluations as leaving the programme they are evaluating unchanged and therefore not putting any additional burdens or requirements on those using

the programme intervention. Thus, the evaluation places no greater risk of harm to patients or users. Weijer *et al*, however, state, ‘researchers collaborate with the government to randomise clusters to intervention or control conditions in order to rigorously evaluate the programme.’¹⁰ and therefore the programmes are not implemented as usual. What follows from this is that ethical evaluations and procedures, as set out in guidance such as the Ottawa statement, are triggered and therefore Watson *et al* are not justified in claiming otherwise. This is an important debate for research ethics and what is appropriate ethical oversight will depend on a finely grained categorisation of the intervention. A sensitivity to the specific context is crucial, so that approvals do not impose a ‘one-size-fits-all’ template on research projects and, as has been often noted, this is something that ethical approval procedures have often struggled with.¹¹

Along with encouraging debate in the form of responses and commentaries on articles, see the responses to Riisfeldt’s article,^{12–16} Weakening the ethical distinction between euthanasia, palliative opioid use and palliative sedation¹⁷ and his reply,¹⁸ we also encourage medical students and students of related disciplines to submit to the journal. In this issue we have a student essay by Conan, on frequently overlooked realistic moral bio-enhancement interventions.¹⁹ In this paper Conan argues that certain bio-enhancements such as transcranial direct current stimulation over the medial and dorsolateral prefrontal cortex, as well as supplementation with lithium and omega-3, have the potential to reduce

antisocial behaviour, reduce racial bias, increase executive function and increase prosocial traits like fairness and altruism. He argues that these interventions are both ethically acceptable and practically feasible and explores ways these should be implemented, ‘especially for violent offenders and public servants—the former as rehabilitation and the latter to meet the high standards of their occupations.’¹⁹

These and the other papers in this issue demonstrate an impressive range of methodological orientations and topics and how, at the start of a new decade, bioethics is well placed to make significant practical and methodological contributions to addressing the challenges that face health-care systems across the globe.

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