Highlights from this issue

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Kenneth Boyd, *Associate Editor*

Ethical decision-making in clinical contexts

Ethical decision-making under conditions of clinical uncertainty can be both complex and difficult. In this issue, particular complexities and difficulties arising in three clinical scenarios are helpfully discussed with a view to their practical as well as ethical resolution. The most generic of these scenarios, discussed by Winkler *et al* (***see page 647***, Editor's choice) is when a patient 'requests active treatment with the goal of life-prolongation while the physician suggests best supportive care only'. The authors, recognising that resolution of this conflict 'requires both medical expertise and value judgements', propose 'an ethical algorithm with five guiding questions' which reflect criteria related to the 'effectiveness' and 'benefit-harm ratio of the intervention', 'the patient's understanding of his or her medical situation' and, in certain circumstances, the 'resources required for the treatment'. This paper, which also includes useful discussion of the concepts of futility and denial, offers an ethically sophisticated but accessible decision model which deserves to be seriously considered by clinicians in the circumstances it addresses.

A more specific decision-making scenario, concerning decompressive craniectomy for patients with traumatic brain injury, is discussed by Honeybul and colleagues and in Madder's commentary (***see pages 657 and 662***). The authors describe the problematic weighing of potential benefits and risks related to this controversial albeit 'technically straightforward' surgical procedure, but go on to ask whether or not a patient might wish it to be carried out, given that while 'many patients go on to make a good long term functional recovery', a 'significant number survive but are left with severe neurocognitive impairment'. The difficulty about answering this question, of course, is that 'the patients themselves will be in no position to participate in any discussion regarding treatment options'. Consequently, the authors argue, 'the fundamental question is what we would want for ourselves if we were unfortunate enough to be in this position'. But studies reporting the risk-averse preferences of healthcare workers were they themselves in these circumstances may not be sufficiently representative to rely on, while prospective preferences may differ from those in the event, and the question of what an individual might prefer also needs to be considered in the light of resource implications which are themselves two-edged. As the authors insightfully observe: 'From a purely utilitarian standpoint it is difficult to justify lifesaving intervention when the *probable* outcome is severe disability with that individual reliant on long-term medical and nursing care at considerable cost to society. However, this position fails to recognise that conveying the message that life is precious and worth a great deal of effort to preserve is in itself a source of social utility'.

Honeybul and colleagues are to be commended for drawing these complex, difficult and, for many surgeons and patients, urgent questions to the attention of a wider audience without pretending that they or anyone else have any easy solutions to offer. As Madder comments: 'The authors' conclusion is clear and should be fully endorsed: all effort should be made to promote an evidence base for the epidemiology and treatment strategies for traumatic brain injury. Only then can we build a framework for ethical management decisions to promote the best interests of the patient and a sustainable society'.

The third clinical scenario involving complex and difficult decision-making also has a specific context. 'Application of Medicolegal Approach in Clinical Stalemates' by Tang (***see page 645***), takes 'the usage of tissue plasminogen activator (tPA) in incidents of acute ischaemic stroke' as a striking example of 'behavioural equipoise' where 'physicians do not concur on a particular issue, despite significant findings from clinical trials' and thus leads to a situation where 'the scientific community enters into a state of stalemate'. This stalemate is unlikely to be broken, Tang argues, simply by conducting further trials in order to try to persuade reluctant clinicians: while these might provide the 'best' treatment for those patients randomised to it, they would be difficult ethically to justify or practically to recruit for. The stalemate might be broken however by adopting a medicolegal approach, in which doctors who do not use the standard of care established by trials and guidelines become liable for negligence. In the case of tPA usage, Tang observes, this might be particularly useful, since most of the relevant cases to date have been 'predominately associated with the failure to provide tPA as opposed to the harm caused by the treatment'. While this approach could have beneficial consequences in this specific context however, Tang argues that it is highly context-dependent and 'may encourage defensive medicine'. 'Only in instances when an intervention is proven but underutilised can this approach maximise its effectiveness'.

Responsibilities of researchers, doctors and editors

The extent of medical responsibility is a multifaceted question, recurrently debated in a variety of contexts. Aspects of this question are considered in four papers in this issue. In their paper on a capacity-based approach to ancillary care needs (***see page 672***) Bright and Nelson contribute a new approach to what is now a well-established area of debate in medical research ethics. What obligations have research clinicians 'to provide care that participants need, but that is required neither to successfully answer the researcher's question nor to avoid or mitigate harm resulting from participation in the research'? Answers to this question now range across an ethically increasingly sophisticated spectrum from prohibiting to prioritising ancillary care. The authors' 'novel suggestion', as Richardson observes in a commentary on their paper (***see page 677***), is that 'within the limits of capability, ancillary-care

obligations apply when and only when the needs addressed are urgent'. Their 'capacity-based model' has 'three tiers: urgency, local capacity, and internal research capacity', and it is accompanied by a decision-tree, which Richardson commends both because it 'is the kind of tool that researchers in the trenches will need when dealing with the great variety of ancillary-care needs that can arise in any study', and also because 'it is readily adaptable'.

While Bright and Nelson's paper discusses ancillary care needs in general, it concludes with the observation that in the particular context of paediatric research in resource limited settings, these needs 'might routinely be urgent'. Even in settings where resources are less limited however, paediatric research can still raise its own special considerations, not least in relation to responsibility for the recruitment and consent of children to research. A significant question in this context is that of what value children themselves place on the research to which their consent or assent to participate is invited. Relevant and useful evidence on this now is made available by Brierley and colleagues in a report of their research on the quantitative valuation placed by children and adolescents on participation in research (***see page 686)***.

The scope of physicians' obligations in a different context—providing emergency care during disasters—is addressed by Akabayashi in his brief report (***see page 697)*** arising from the 2011 earthquake, tsunami and release of radiation from the Fukushima nuclear power plant in Japan. Urgency and capacity again are seen as important considerations when determining medical 'obligations of beneficence', but in what may be highly dangerous circumstances, so too, the author argues, are 'significant risks, costs, or burdens' to the physicians involved or indeed to their existing patients. In emergencies, moreover, it can be 'exceedingly difficult to obtain detailed and accurate information for proper risk-benefit assessment': more specific guidelines may be needed to interpret the implications of general beneficence for physicians in the eventuality of nuclear disasters.

Guidelines and responsibilities nearer to home for us are the subject of a paper on the potential conflicts of interest of editors of medical journals, by Smith (***see page 679)*** and a commentary by Marcovitch (***see page 685***). Smith's paper is concerned not so much with whether medical journals have policies to deal with editors' as well as with authors' and reviewers' conflicts of interest, as with whether any such policies they may have are transparent and accessible to their readers and the public. The author's reported survey of leading medical journals suggests that only a minority do have accessible policies which refer specifically to editors' conflicts of interest; and this, Smith suggests, 'may have a negative impact on the trust accorded to these journals'—a concern which Marcovitch, citing other studies on the subject, shares.

Other papers in this issue

The remaining papers in this issue comprise three contributions to areas of debate already well-known to readers of this or other ethics journals, while four others are on issues which may be less familiar. In the former category, Janssens *et al* add further insights to discussion of euthanasia in the Netherlands in a paper (***see page 664***) problematising guidelines which represent palliative sedation as normal medical practice. In his paper on Jehovah's Witnesses and autonomy (***see page 652***) Bock both defends Witnesses from claims that their beliefs are irrational, and more generally attacks the requirement of rationality as a basis for informed consent. And responding to arguments by Agar, Persson discusses whether it could be permissible to prevent the existence of morally enhanced people. Perhaps less familiar but no less important ethical issues are discussed in contributions by Shaw *et al* on sobriety testing in Scottish criminal justice (***see page 669***), Mercieca *et al* on the freedom of movement across the EU of children with chronic disease (***see page 694***) and Rosselli *et al* on rare diseases in ethnic minorities in Colombia (***see page 699***).