

# Responding to complexity

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doi:10.1136/medethics-2014-102070

The papers in this issue of the *Journal of Medical Ethics* address various aspects of five familiar areas of bioethical enquiry: transplantation, genetics, euthanasia, research ethics and professional practice. That these areas, despite all that has been written about them, continue to provoke productive scholarly attention, testifies not only to their existential relevance but also to their moral complexity. Countless human lives will be affected, for better or worse, by how moral decisions in these areas are taken, communicated and implemented. It is of the greatest importance therefore that the ethical thinking informing not only such decisions but also the practices of which they are part, should be both principled and appropriately contextualised. To that end, familiar moral attitudes, assumptions and arguments require repeatedly to be challenged from a variety of perspectives, not ultimately to discover any definitive unravelling of moral complexity, but rather to inform more thoughtful and nuanced responses to the diverse manifestations of that complexity. As Calbresi and Bobbitt have observed: ‘a moral society must depend on moral conflict as the basis for determining morality’.<sup>1</sup> The papers in this issue, written from a variety of cultural, as well as ethical, legal and clinical perspectives, each can assist in that process.

For over half a century the subject of organ transplantation has attracted ethical debate. One such ongoing debate, provoked by the severe scarcity of organs for transplantation and a concern to increase their supply, has been about why willing live donors should continue to be prohibited from offering their own organs for sale. Against allowing this, it has often been argued that prohibition protects people in poverty from being driven to, and then harmed by, this desperate last resort. But is that how such people in poverty themselves see it? From their point of view, it has been suggested, wouldn't it be reasonable to see prohibition as depriving them of their best option, leaving them worse off than if they had been able to exercise it? Isn't the claim to protect people in poverty therefore ‘misplaced paternalism’, providing no ethical justification for prohibition?

In this month's feature article, Simon Rippon (*see page 145*, Editor's choice)

mounts a serious and sustained challenge to that conclusion. He argues that while it would be reasonable for people in poverty to sell their organs if given the option, it would be equally reasonable, given the ‘significant and unavoidable’ harms of a live organ donor market, for them to prefer not to have this option at all. In her commentary on Rippon's paper, Janet Radcliffe-Richards (*see page 152*) acknowledges that ‘a plausible case for prohibition would probably take this form’, but goes on to argue that ‘although in principle prohibition need not be paternalistic, in practice it is’, since it ‘has been imposed on everyone irrespective of any consultation’. To this, and two further commentaries, by Gerald Dworkin (*see page 151*) and by Adrian Walsh (*see page 153*), Rippon responds (*see page 155*) in a significant contribution to a debate that nevertheless seems likely to continue unabated as long as the need for whole organs continues so greatly to exceed their supply.

A more recent development in transplantation, live liver donation, raises some rather different ethical issues in a paper by Elin Thomas and colleagues (*see page 157*). This reports on their study of British healthcare practitioners involved in negotiating acceptable degrees of risk for related and stranger donors, and expresses concern about the extent to which relevant decisions, in the absence as yet of reliable evidence, may have been influenced by the healthcare practitioners' own subjective values.

Ethical issues related to paternalism are also raised by Wendy Bonython and Bruce Arnold (*see page 168*) in their discussion of recent Australian genetic privacy law. This set out to ‘permit disclosure of an individual's genetic information, *without their consent*, to genetic relatives’ but subsequently was amended in delegated legislation by means and in ways which appear even less consistent with respect for consent and confidentiality. This highly informative account of Australia's brave but flawed attempt to tackle the thorny issue of unconsented disclosure of genetic information to other family members deserves study by lawmakers and clinicians alike.

A no less difficult aspect of disclosure of information to family members is

discussed in a paper by Pamela Tozzo and colleagues (*see page 177*) on the discovery of misattributed paternity in genetic counselling, which compares contrasting Italian and British guidelines and practices and suggests ways in which these might be harmonised in a European context. And a final paper on genetics again suggests a new angle to a familiar issue. Alison Hall and colleagues (*see page 163*) examine the arguments for and against the genotyping of children as part of a personalised screening programme for common cancer. Usual arguments against predictive genetic testing of children for strongly penetrative adult-onset diseases, they suggest, may be less persuasive in the presence of a combination of much more weakly predictive common genetic variants, which can later enable potentially beneficial risk-stratified screening.

New perspectives on the much-debated subject of euthanasia are provided in two papers and a commentary which explore cultural differences in attitudes toward it and related issues. In a psychological investigation of attitudes in Iran, Nasir Aghababaei (*see page 173*) explores how altruism and other personality variables relate to how different aspects of euthanasia and its acceptability are framed. His conclusion, that both culture and personality influence this, is echoed but with more emphasis on religion, in a paper by Shanmukh Kamble and colleagues (*see page 186*) on attitudes to the acceptability of actively ending the lives of newborns with genetic defects, among Muslim Kuwaitis (broadly opposed in all circumstances) and Indian Hindus (more in favour, but also context related). Commenting on this, Ayesha Ahmad (*see page 192*) argues for greater recognition and understanding of the role and influence of culture – including Western scientific culture – on the global practice and ethics of medicine.

In the first of two further papers related more broadly to end of life issues, Tak Kwong Chan and George Lim Tipoe (*see page 202*) make a strongly persuasive case against the continued appeal in English courts to it being in the best interests of a patient in a persistent vegetative state to be allowed ‘to die with dignity’. Their recommendation that it is sufficient to consider only the futility of treatment

includes a helpful account of that sometimes slippery concept. The final paper related to this theme, by Benjamin Herreros and colleagues (*see page 205*) is an account of the development of clinical ethics protocols by clinical ethics committees in Madrid: the most frequent topics addressed by these are end of life issues and refusal of treatment.

The two papers on research ethics included in this issue both emanate from the United States. One, by Elizabeth Pike (*see page 182*) addresses a specifically American problem, that of US policy for compensating – or in many cases not compensating – injured research participants. The degree of injustice involved in this, the paper argues, can only be rectified by the US adopting ‘systemic no-fault compensation injustice’ to bring its law ‘into accord with global ethical norms’.

The other paper, by Robert Klitzman (*see page 193*) on how US institutional boards decide when researchers need to translate studies (and of how they weigh informed consent against cost), is perhaps of more universal interest and application.

Finally, three papers on the ethics of professional practice are included in this issue. One of these is concerned with new possibilities for travel, the second for technology. Adelaide Conti and colleagues (*see page 209*) address the problems, including those of continuity of care, arising from Italian patients traveling to Eastern European countries for less expensive dental treatment. Rhys Van der Rijt and Stuart Hoffman (*see page 211*), by contrast, explore the therapeutic possibilities and ethical pitfalls presented by clinical photography in an area of emerging technology and smartphones. The

final paper, by Sandra Zweir (*see page 198*), more controversially, challenges received opinion on the appropriateness of banning physician advertising. While many ethical arguments have been made, and have largely been accepted, against advertising by physicians, the ethical repercussions of having such an advertising ban itself, Zweir believes, have been mostly overlooked: such a ban, she argues, keeps patients in the dark about the physician’s interests and the possibility of alternative treatments, effectively leaving patients no option but to ‘maintain a good relationship with the physician in order to ensure future quality care’.

#### REFERENCE

- 1 Calabresi G, Bobbitt P. *Tragic Choices*. New York: WW Norton & Company, 1978:198.