

The concise argument

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Consent—an issue that will not go away

Informed consent is one of the perennial problems of medical ethics. It raises interesting philosophical questions, but also questions about regulation and implementation. The paper by Fovargue and Miola in this issue look at the recent guidance to doctors on informed consent from the UK's General Medical Council (*see page 494*). They reach the rather depressing conclusion that whereas the law in the UK has moved forward in the recognition of patient autonomy, the GMC has moved backwards in some areas since the previous guidance was issued in 1998.

A paper by Potts *et al* also look at consent, but in this case consent to organ donation (*see page 498*). They criticise a paper by Ben Saunders published in the JME in 2010. Saunders combined David Estlund's concept of 'normative consent' with Peter Singer's 'greater moral evil' principle and argued on this basis that actual consent to organ donation after death is not necessary, only absence of a clear refusal. Potts and co-authors first argue that Saunders' argument shows more than realises, or at least more than he made explicit in his paper. If Singer's greater moral evil principle is taking seriously there are very few things that could take precedence over life saving and refusal to donate could therefore only be justified in very rare circumstances. Saunders therefore ought to support 'mandatory consent' but such a policy would, according to Potts *et al* by excessively totalitarian. The second criticism is that it is questionable whether all organ donors are actually dead before the donation process begins and therefore not obvious that anyone has a duty to consent to live, but death inducing organ donation.

Implementing patient rights

Affording patients a range of legal rights is one way to protect their moral rights and

their interests. But merely stating in law and regulation that patients have these rights is not in itself sufficient to lead to a situation where these rights are also respected in actual healthcare practice. A systematic system and process for implementing the rights is also needed. The paper by Saracoglu *et al* describes Turkish experiences with a particular system for supporting and implementing patient rights (*see page 488*). The study shows that by putting in place the right structures changes can be achieved and more patients have their rights respected.

Incentivising medication adherence

There is an increasing interest in developing schemes that incentivise patients for pursuing behaviours that are seen as appropriate and in their best interest. Such schemes are, for instance being trialed in relation to obesity and physical exercise and in relation to medication adherence in psychiatric patients. The paper by Priebe *et al* uses a focus group design to investigate the views of stakeholders on the ethical problems in offering financial incentives to out-patients with severe psychotic disorders if they adhere to their anti-psychotic drug regime. The study included 25 groups with stakeholders ranging from patients to health economists and non-executive directors of healthcare trusts. In the discussion of incentive schemes there has been a tendency to focus on either paternalism or coercion as 'The ethical problem' that has to be solved or circumvented. The paper does, however show that the situation is significantly more complicated and that the range of important ethical issues is much wider. It divides these into four categories: (1) 'wider concerns', including the value of medication, source of funding, how patients would use the

money, and a presumed government agenda behind the idea; (2) 'problems requiring clear policies', comprising of practicalities and assurance that incentives are only one part of a tool kit; (3) 'challenges for research and experience', including effectiveness, the possibility of perverse incentives, and impact on the therapeutic relationship; (4) 'inherent dilemmas' around fairness and potential coercion. As the paper points out only some of these concerns can be addressed by policies.

Making the abstract personal – confidentiality and donor insemination

Discussions in medical ethics sometimes proceed at a fairly abstract level and if empirical data about the effects of certain policies are adduced it is most often from social science research. The actual voices of those who face ethical dilemmas or whose lives are profoundly affected by medical interventions are rarely heard in an unmediated form. We are happy in this issue to be able to publish a paper that begins to redress this imbalance (we would probably have to publish several years worth of papers to really redress it). Mary Wood provides a powerful narrative of her experience of having two children with a sperm donor who was later discovered to carry a gene for a serious heart disease (*see page 479*). Her narrative casts light on the immense complexity that often goes into decisions concerning assisted reproduction and on the long and unpredictable chain of consequences that follow such decisions. These consequences are not only cognitive but goes to the root of what it means to be a family. If you read nothing else in this issue, READ THIS!!!