Guest Editorial

A Complex Web of Questions

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This *CQ* special section on consent and organ donation is both timely and policy relevant. Organ donation policy continues to generate considerable interest not only within the academic community but also among healthcare professionals and the wider public. There are at least three main reasons for this.

First, the very nature of transplantation makes it an unusual and interesting area of healthcare. It involves either making use of a person's body after death or performing a procedure on a living donor that is not aimed at benefiting that person, often exposing him or her to additional harm or risk. In these respects, transplantation more closely resembles some types of biomedical research than it does the rest of clinical practice.

Second, the shortage of transplant organs is a major global problem. The UK Organ Donation Task Force report, for example, noted that although in 2006–7 more than 3,000 patients in the UK received an organ transplant, another 1,000 died while waiting or after being removed from the waiting list because they had become too ill. The national waiting list at that time stood at 7,235, a figure that has been increasing by 8 percent each year. Furthermore, the waiting list size does not fully reflect the actual level of need, because doctors are sometimes reluctant to list patients who they do not believe stand a realistic chance of receiving an organ in time.[1] Similarly, approximately one million Americans are estimated to be on transplant waiting lists, with a further million people in China requiring organ transplantations of various kinds.[2]

Third, organ donation is a sensitive and emotionally charged topic on multiple levels. Although relatives may take comfort from knowing that the death of their loved one has helped others to live, in other situations, they may be distressed by the idea that the body is no longer "whole." Especially in cases of living donation, ideas of heroism, altruism, and the gift relationship carry considerable weight in the public imagination despite some academic critique.[3]

Consent has a central role in all the issues mentioned previously and is the overarching theme that links the articles that form this special section. Arguably, consent is an important moral justification for making use of people's bodies after death as well as for exposing living donors to additional risks. Getting consent policies right is an important part of increasing or maintaining the supply of organs. The idea that donation should always require consent is a fundamental

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aspect of many people's thinking about the gift relationship, one that serves to promote public trust in our donation systems.

The following articles explore the multifaceted issues involved with consent highlighted above and, using examples and experiences in the UK, address the wider implications on an international scale.

In the first article, "Reflections on the Nature of Public Ethics," Jonathan Montgomery describes the political difficulties that underpin organ donation policy by drawing on his personal experience as a member of various bodies appointed to advise government. He explores the differences between the activities of ethical deliberation in the academy and in the public domain. He draws attention to the collegiate nature of committee work, the constraints imposed by committees' constitutions, and the need to incorporate attention to the sociopolitical context into both the work of those groups and also academic critique of their products. Montgomery argues that such "public ethics" is fundamentally a contingent process; it is driven by pragmatic arguments rooted in particular times and places and is dominated by politics rather than bioethics. He proposes that if this is correct, the reports of advisory bodies should be assessed on a different basis from academic papers and should be regarded more as historical documents than works of principle.

David Price and Jo Samanta, in their article "Supporting Controlled Non-Heart-Beating Donation: An Ethical Justification," highlight the tensions between appropriate structures for improving organ donation outcomes and handling the difficulties around the dying process. Responding to an article by Gardiner and Sparrow (*CQ* 2010;19:17–26), they propose that these tensions are not as great as they at first appear and argue that the best interests of the individual should not necessarily be seen as in opposition to improving outcomes for donation. They suggest that, when assessing the best interests of a particular patient, we need to move beyond simply discussing medical best interests and instead take a more holistic approach. For individuals wishing to be organ donors, their intention should be taken into account when assessing their best interests. The authors argue that it is both ethically and legally acceptable to continue with ventilation, even when it is futile in a curative sense, if this will have a positive impact on the probability of transplant success, thus fulfilling the wishes of the prospective organ donor. Even when ongoing ventilation is not in the *medical* best interests of an individual, it may nonetheless be part of his or her *overall* best interests.

Debates about consent and organ transplants often center on the type of consent system to be adopted. In setting up a system for obtaining consent, the options are frequently taken to consist of an *opt-in* system (in which it is presumed that people have not consented to their organs being used after their death unless they specifically consent to this use), an *opt-out* system (in which it is presumed that they have consented to their organs being used unless they have specifically stated that they do not), or a *mandatory choice* system (in which everyone is required to express a view about whether their organs should be used after death). More recently, an alternative to these standard options, *normative consent*, has been proposed. According to advocates of a normative consent model, we are entitled to treat those who have not consented to the use of their organs postmortem as if they had consented, because it would have been wrong of them not to have done so. In his article, "Normative Consent Is Not Consent," Neil C. Manson sets out to explain and draw out the implications of this model. He argues that objections to normative consent in the literature are frequently based on a misunderstanding of the concept. He argues that, in fact, it is misleading to call this a consent model at all, as normative consent is not in fact consent, and furthermore that the model implies a radical departure from the assumption underlying all of the standard models that it is wrong to use organs postmortem without consent.

In contrast to the other authors in this collection, who focus on the use of organs postmortem, Govert den Hartogh's article, "Is Consent of the Donor Enough to Justify the Removal of Living Organs?," considers the ethics of living donation. Although it is generally accepted that living donation should be allowed, serious concerns still remain over some forms of living donation—including anonymous donation, directed donation, and paid donation. Den Hartogh begins by considering the ethical acceptability of indirect paternalism and its relation to the professional morality of doctors. He argues that indirect paternalism is not subject to the same objections that have made direct paternalism morally problematic. He goes on to consider the extent to which indirect paternalism can justifiably be used to prohibit some forms of living donation. He argues that although some forms of directed donation may be acceptable, others, such as anonymous donation directed to a stranger, are not. Similarly, he maintains that although indirect paternalism may in many cases justify the prohibition of the sale of one's organs, this restriction is more limited than previous arguments have suggested.

Questions about the consent of individuals whose organs are to be used have been center stage in the organ debate. But questions about the role of the family in giving consent to the use of organs after death have also been significant. In their article, "'Keeping Her Whole': Bereaved Families' Accounts of Declining a Request for Organ Donation," Magi Sque and Dariusz Galasinski discuss bereaved families' accounts of declining a request for organ donation. Through methods of discourse analysis, Sque and Galasinski explore the underlying reasons families chose to refuse requests for donation. A common theme that emerges from their analysis is that it is the family's concern for the integrity of the body and keeping their loved one whole that often determines donation refusals. However, as their article demonstrates, there are complex underpinnings to the construct of "keeping her whole." The authors highlight how speakers place themselves at the center of the decisionmaking process, and they tease out how it is often the family member who cannot bear for donation to happen; it is they who cannot donate. Their study, the first to focus on families who refuse requests to donate organs, suggests some ways in which requests for organs can be changed in order to achieve a more positive outcome.

In the final article, "Organ Transplantation, the Criminal Law, and the Health Tourist: A Case for Extraterritorial Jurisdiction?," Jean McHale considers the issue of "transplant tourism." She points out that there is growing empirical evidence showing that individuals are traveling outside of the UK to procure an organ, often through commercial exchange. This reality raises many ethical issues. Are these individuals jumping the queue? What is the impact on the National Health Service (NHS) for returning patients? Also, what are the legal implications of these individuals' actions? The UK's Human Tissue Act 2004 strictly prohibits the commercial sale of organs for transplant. So, McHale asks, how should the law deal with individuals who evade domestic prohibitions by traveling abroad? She proposes several options, including the possibility of extraterritorial jurisdiction to make the domestic prohibition binding on those traveling outside of the country. Such a policy would probably involve primary legislation amendments and be difficult to enforce. McHale provides an overview of current international guidance in the area that highlights the consensus that exists regarding prohibition on the sale of organs. Given this consensus, which implies that the prohibition on organs is something that is important both legally and ethically, perhaps—rather than allowing the difficulties of enforcement to lead to dismissal of extraterritorial enforcement out of hand—these difficulties must be overcome.

As demonstrated in this collection of articles, the issues of consent for organ donation form a complex web of questions involving setting public policy, determining what counts as consent, recognizing what influences refusals, and addressing the role of law. All the dilemmas raised, along with the intertwining of legal and ethical complications, pose specific challenges, and although no claims are made for resolutions, clarifying distinctions, exposing errors in analysis, and advancing arguments are significant contributions.

Between the time of the workshop and the publication of this special section, we were all saddened to learn of Professor David Price's death. David was a wonderful colleague and a leading expert on the many legal and ethical issues raised by organ donation policy. He was admired and respected by so many within the academic community and far beyond. He will be greatly missed.

Notes

1. Department of Health (UK). *Organs for Transplant: A Report from the Organ Donation Taskforce*; 2008 Jan; available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_082120.pdf (last accessed 27 Aug 2012).
2. Knoll G. Trends in kidney transplantation over the past decade. *Drugs* 2008;68 Suppl 1:3–10.
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