

Bodies, organs and saving lives: old respects and new dilemmas

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ABSTRACT – Attitudes to death are non-rational and culturally determined. This is relevant to concerns about shortages of organs for transplantation. Consent is not possible from a dead donor and the term ‘resumed consent’ offends against the principle of respect for autonomy that underpins consent. Consent is the fundamental principle of the Human Tissue Act 2004 in considering use of organs after death. These legal and ethical concerns create difficulties to be explored in a subsequent paper.

KEY WORDS: brain stem death, consent, Human Tissue Act 2004, organ retrieval, organ transplantation, Redfern Inquiry, transplant

Over 20 years ago, Richardson published her brilliant study on death in 19th-century Britain.¹ Today, she observes, preparation of the dead for disposal is seen as a sanitary problem, dealt with professionally by hospitals and undertakers. By contrast:

in folklore, this process, with its intimate knowledge of the physiology of putrefaction, was counterpoised by a profound conception of the corpse's metaphysical attributes. This is reflected in a number of beliefs and rituals.

She comments that there seemed to exist a conception of a period between death and burial in which the human being was regarded as neither alive nor fully dead. An extreme and amusing example is the Welsh baronet, Sir John Price, who kept the embalmed bodies of his first two wives in his bedroom, but on the death of the third requested Bridget Bostock, the local healer (by prayer and ‘fasting spittle’), to raise her up. Bridget refused to oblige: either she had conscientious scruples or a due sense of her limitations.²

In another magisterial study, Keith Thomas observed how in England the loss of belief in purgatory led by 1649 to the comment that burials were ‘in a manner profane, in any place the dead being thrown into the ground like dogs, and not a word said.’⁴ These developments paved the way to the hasty embarrassed funerals of today.³ The power of the newly dead to heal was thought useful, even by so distinguished a scientist as Robert Boyle, for example in treating goitre by touching the hand of a freshly hanged man.³

William Harvey, who proved the circulation of the blood, based his findings ‘by autopsy on the live and dead’. His untypical

clinical detachment led him to dissect both his own father and sister *post mortem*. However the 16th-century enactments that gave the Companies of Barbers and Surgeons annual right to the body of four hanged felons, demonstrates the link between dissection and punishment. Dissection was, Richardson points out, an aggravation to execution and a fate worse than death. The surgeon-anatomist became an executioner of the law. The spectacle of dissection was a punishment inflicted on the wrongdoer, differing only from the punishment of hanging, drawing and quartering in that it aspired to advance medicine. It was, as the 1752 act of parliament said, a ‘further Terror and peculiar Mark of Infamy’.¹ Attitudes changed through the 18th and 19th centuries. Even while combating the morbidity of the deathbed scene, Porter states out that ‘rational Christians, Deists, sceptics and atheists alike sought to demystify death by promoting a frankness towards physical annihilation’.⁴

Although ‘strange lingering echoes of the old devil worship might perhaps even now be caught by the diligent listener among the grey-haired peasantry’ most of us will read past accounts as something long left behind us.⁵ The suggestion of a period of being neither fully alive nor fully dead, for example, belong to superstitious past. Thus ‘on an atomic level, every breath we take contains stuff that was once someone else’.⁶ Yet, across a variety of cultures, we give special respect to the body. We are not indifferent to its treatment after death. It was the former embodiment of personality, the remains of someone we loved or respected and, as such, worthy of special respect. It should be honoured, treated with care, disposed of with some ritual. We are disturbed by pictures of bulldozers dumping bodies into mass graves as concentration camps were cleared. I found myself shocked to read aloud extracts from Jonathan Swift’s 1729 satirical essay on *A modest proposal* which proposed eating children to solve the Irish population problem:

*What is it, in the self's eclipse,
Shadows, soft and passingly,
About the corners of her lips,
The smile that is essential she?
And if the spirit be not there,
Why is fragrance in the hair?*⁷

Language, belief and concepts

Our language indicates this special status. Between April 2006 and March 2007, relatives gave the following reasons for refusing organ donation:

- the patient had suffered enough (13%)
- not wanting surgery to the body (18%).

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Do we consider this respectful or merely superstitious? As for more general usage, we still talk in metaphor of 'laying someone to rest' or of a last 'resting place' or of 'falling asleep'; people do not die, they 'pass away'; perhaps more prissily, there are no dead only the 'deceased'; no next of kin, only 'loved ones'. I suspect that referring to a patient declared dead after brain stem tests as a 'corpse' would be highly offensive. Language provides a key to our culture and our understanding. Words have their own peculiar resonances – as the editor of *Clinical Medicine* found to his cost not long ago.⁸ The word 'starvation' conjures up the image of the pot-bellied marasmic Biafran child, not the nutritionally deprived patient on hospital wards.

Where death is concerned, our attitudes may be strictly non-rational, but this is not at all the same thing as alleging that they are 'superstitious'. We do not avoid cannibalism because of the risk of slow viruses. In debates over organ removal, there are cultural reservations that may be as 'rational' as the utilitarian belief in maximising the welfare of others. To quote Porter:

*Death affords a good instance of the scope for different interpretations in the light of different criteria. The nature of 'physical' death is highly negotiable; in recent times western tests have shifted from cessation of spontaneous breathing to 'brain death'. This involves more than the matter of a truer definition: it corresponds with western values (which prize the brain) and squares with the capacities of hospital technology. Some cultures think of death as a sudden happening, others regard dying as a process advancing from the moment of birth and continuing beyond the grave. Bodies are thus languages as well as envelopes of flesh.*⁹

Pallis, a pioneer in developing the concept of brain stem death, emphasised the importance of the philosophical understanding of death: in his view, death of the organism as a whole.¹⁰ It is not irrational to think otherwise. Two personal anecdotes illustrate this. Organ removal had been refused in a patient with intracerebral haemorrhage. Tests for brain stem death were done, the ventilator switched off and, being a Sunday afternoon, I went home. A little later, I was telephoned to ask me to come back and certify the patient as dead, the heart having now stopped. 'But,' I protested, 'that is what I did nearly an hour ago.' 'Ah no', the intensive care sister replied, 'he's properly dead now'. Clearly for her, despite a considerable experience, brain stem death was a sort of death, but not quite a proper one – perhaps a convenience for something else: of which the obvious 'something else' would be the transplant programme. A second experience involved a young person whose brain stem tests had indicated his death more than 24 hours previously. Here the intuitions were those of the family. The patient was not dead and might rise again like the Lazarus of the gospel narrative.¹¹ How could a patient who was warm, with heart beating, producing urine, maintaining a blood pressure be 'dead'? To the physician, the answer seems obvious, but we have to acknowledge that our answer involves some underlying assumptions.

One practical conclusion from this might be that those of us who are enthusiastic supporters of transplant programmes should avoid making others feel guilty who do not share our

values. We may wish to promote the 'gift of life', but there are reasonable objections. Altruism is not compulsory. We are not prohibited from spending our money on luxuries when we could use it to save lives.

A second conclusion might be that we should take special care in changing public policy where cultural beliefs impact upon law making. Recent debate has tangentially acknowledged these concerns in noting that whereas nationally the relatives of 40% of potential donors refuse consent to donation, this is 75% in the case of those from a black and minority ethnic (BME) background. The 2006 report of the chief medical officer (CMO) noted that 2% of renal donors are from BME backgrounds, compared to 18% of recipients.¹² There are also significant differences between geographical areas of the UK. It is not adequate to assert that a particular policy has been accepted in another jurisdiction. There is work to be done in exploring the options. It has yet to be undertaken. Considering that the first human renal transplants were attempted in 1951, this is perhaps disappointing.⁹ Surely we should assess all reasonable options – those we favour and those that we do not.

Organ shortage

The adequate availability of organs for transplantation is a long-standing issue. In a 1972 report, for example, the supply of cadaveric kidneys was a 'major problem that limits the further expansion of transplantation'. Yet it was thought that there were more than enough potential donors available.¹³ A further report in 1987 said little new.¹⁴ As transplantation expanded, so too has the organ shortage. Currently between 7,000 and 8,000 patients await transplant and the numbers are rising by 8% per year.¹⁵ For those hoping for this gift of life, the word 'crisis' is no overstatement. Such patients endure the shortcomings of current medical therapy, awaiting the telephone call and wondering whether death will call first.

These rising numbers have led to:

- discussion in the 2006 annual report of the CMO with the proposal of an opt-out system¹²
- a policy communication from the EU Commission to the European Parliament
- an inquiry by the House of Lords Select Committee on the EU, including a public consultation
- the adoption by the British Medical Association (BMA) of a policy advocating so-called 'soft presumed consent'
- a government-sponsored Organ Donation Taskforce (Organs for Transplants)¹⁵
- a report of an *Inquiry into presumed consent for organ donation* to the National Assembly for Wales, published in July 2008¹⁶
- an independent report following the taskforce report on *The potential impact of an opt out system for organ donation in the UK*, published in November 2008.¹⁷

The Organ Donation Taskforce report directs the reader to a number of issues that need to be addressed.¹⁵ These included

ethical difficulties for example the quality of consent with the current donor card:

Amongst clinicians there is a certain amount of concern that the carrying of a donor card, or even registration with the donor register, falls short of what would usually be defined a consent in a medical setting. Furthermore... the passage of time between registration and death is seen by some to weaken the ethical force of the action. These concerns cannot be ignored... (para 4.8)

Secondly, (para 4.11):

having made a decision to withdraw treatment from a patient who is known to be a potential donor, one faces the ethical question of whether it is morally acceptable to manage the process of treatment withdrawal and the death of the patient in the interests of ensuring the best possible retrieval of the organ.

The report continues (para 4.12):

if we are unclear about the value of the consent, or where no wishes have been stated, we would have to concede that some of the actions taken to facilitate donation may not necessarily be in the interests of the donor.

It would be treating one patient not as an end in themselves, but as an object to promote another's ends. It was a policy of this sort in Exeter some years ago that was declared illegal when patients were identified and treated as potential donors – even though it doubled the number of organs retrieved.¹⁸

Thirdly, the first taskforce report avoided any detailed discussion of policy on obtaining consent to organ retrieval. However it noted the different donation rates between native UK populations and those from a BME background, as detailed above.

If possible, any method of improving organ supply should address all of these concerns. If that ideal can be achieved, at reasonable cost, the ethical case becomes compelling for that policy. Some have been bold enough to suggest dispensing with all forms of refusal and mandating organ retrieval. Few advocate such a policy in public. Forbidding refusal to retrieve organs would, most of us agree, be unacceptable in a free society. The cost would be too high in the values we sacrifice. Yet any course of action may involve some calculation of benefit against harms, where harms may include limitation on certain freedoms.

Consent and organ retrieval

The Human Tissue Act 2004 established that consent is the fundamental principle underpinning the use of organs from the bodies of deceased persons. It is lawful to use the organs of dead people only if there is what is called in the English legislation 'appropriate consent' and what is called in the Scottish version 'authorisation by an appropriate person' (The Human Tissue (Scotland) Act 2006). Despite different wording, the expectation is that the same actions will be legal in both countries. The act therefore creates an obstacle to the removal of organs where the patient (I will use this contentious word for want of a better) has not indicated consent in an advance directive (which, for this

purpose, can be defined as a donor card). A change in the law is needed to realise the proposal of the CMO or of the BMA.

The Redfern Inquiry¹⁹ that followed events at Alder Hey Hospital pointed out that the Human Tissue Act 1961:

was drawn up against a backdrop of advice from the Minister for medical practitioners to obtain the 'consent' of relatives, where available, in relation to the removal of eyes for cornea grafting. (para 9.1)

It seems ironic therefore that we are now considering amending the subsequent Human Tissue Act 2004 in order to facilitate organ transplantation. The Redfern Inquiry goes on to note that 'there was no suggestion that the doctor had to enquire as a matter of routine beyond the next of kin if they did not object' (para 9.2). The terms of the act were that 'having made such reasonable enquiry as may be practicable', there would be 'no reason to believe that any surviving relative of the deceased objects to the body being used in particular for medical education and research purposes' (para 24.1). As the government's consultation document, *Human bodies, human choices* emphasised in 2002, specific consent was not required by the act (para 3.5).²⁰ The unsatisfactory nature of this led to the Human Tissue Act 2004.

Once again we are at the mercy of language, for the proposal for an 'opt-out' system of organ retrieval has been widely referred to as 'presumed consent'. Yet consent cannot be presumed. Anyone might like to presume anything about the choices of another person and call it 'presumed consent'. Plainly it is not and it seems deceitful to use language that implies that, somehow, it is. We must ask why a policy of lack of objection that was unacceptable in the Redfern Inquiry in 2002 should become acceptable now. As McClachlan states:

To say that it can reasonably be presumed that we consent to donate our organs if we do not specifically say that we do not consent is absurd. It is a deceitful piece of sophistry. There might be a good utilitarian case for having an opt-out rather than an opt-in system of organ donation. However, this would mean that there is a case for using our organs even in the absence of our consent. If consent matters in this area, then only the explicit consent of the people concerned can justify the using of their organs after their deaths. If consent does not matter and the use of their organs can be justified without it, then consent does not matter. We should not appeal to the bogus notion of presumed consent.²¹

Some might feel that using terms like 'deceit', 'bogus' or 'fiction' is unfair.²² But, as Erin and Harris point out, however well intended the outcome, the language of consent attempts to disguise what we are actually doing, which is appealing to a principle of respect for individual autonomy. In reality, by presuming we are acting against that principle, we are being disrespectful of autonomy. However we present it, we are actually articulating a particular society's view of what it is morally supportable to do with a dead body. Presuming consent is an affront to the moral principle that is the foundation of consent itself.²²

The further linguistic implication should be noted. If I freely consent, I give something; if I do not consent, it is taken from me. A policy called 'presumed consent' can only result in the retrieval of organs, not in their donation.

These objections are not, of course, lethal to the proposal to legislate for an opt-out practice. The policy could still be right even if its title is wrong. Many who support 'presumed consent' for organ retrieval use alternative names: opt-out systems, presumed lack of objection (PLO), presumed compliance and others. Nevertheless there is disquiet among many – perhaps around 40% of the population – at the possibility of organ removal without advance consent. If there was a strong conviction of the rectitude of a policy of presuming lack of objection, the answer might be more strident or more subtle campaigning to increase its public acceptability. The proposal for PLO has been around for over 20 years so there has been ample time for such advocacy, but rather less enthusiasm. At that time, one of the UK's leading transplant surgeons wrote, for example:

*This is now the law in France, Switzerland and the Scandinavian countries, but it seems to me to suffer from several drawbacks... there is no convincing evidence that it has worked in practice, and it does nothing to enlist the cooperation of staff in intensive care units.*²³

The debate at the time centred on a rights-based approach and possible required request laws. However, it was observed then that:

*while alive we have an interest that other interests will be recognised and served after our deaths. This may include organ donation. The principle of justice (here towards renal recipients) would suggest a moral obligation at least to indicate our wishes, ante mortem. If this were the norm, request of any sort would be unnecessary.*²⁴

In the paper that will follow in the next issue of *Clinical Medicine*, the further problems of PLO will be explored and the implications of this view of justice discussed.

Declaration of interest

JS is chairman of the Committee for Ethical Issues in Medicine, Royal College of Physicians (RCP). The views expressed in this paper are personal and do not represent those of the RCP.

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