Absence of significant dissent should be sufficient for deceased donor organ procurement in New Zealand

Thomas Douglas
Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy, Oxford University, Oxford, United Kingdom

Nicholas M Douglas
Menzies School of Health Research, Darwin, Australia and
Centre for Tropical Medicine, Nuffield Department of Clinical Medicine, Oxford University, Oxford, United Kingdom
ABSTRACT

Objective. New Zealand’s organ donation rates are among the lowest in the OECD. In a bid to increase organ availability, the New Zealand Human Tissue Act 2008 introduces new consent arrangements for deceased donor organ procurement. This article assesses these new arrangements and presents the case for further reform.

Approach. Our assessment and arguments are based on philosophical analysis informed by empirical data on the effectiveness of alternative consent systems. We (1) identify widely held ethical judgments about policies and practices relevant to organ donation (for example, those relating to coronial post-mortems), (2) assess the implications of these judgments for the Human Tissue Act proposal and the assumptions that underpin it, and (3) derive policy recommendations that are consistent with the judgments.

Conclusion. The Human Tissue Act 2008 retains a strong consent requirement for organ procurement: organs may not be transplanted unless either the deceased or the family consents. We argue that organ availability could and should be increased by shifting from a model that requires consent to one that requires the absence of significant dissent.

Implications. We recommend that New Zealand adopt either (1) an organ donation system similar to the existing system for ordering coronial post-mortems, or (2) a variant of the ‘opt-out’ system already in place in several other countries.

KEYWORDS

New Zealanders continue to die while waiting for transplantable organs. Plausibly, some of these deaths could be prevented by relaxing the consent requirements for deceased donor organ transplantation. However policymakers must balance the good of saving lives against the need to respect the wishes of individuals regarding the treatment of their bodies, and those of their loved ones, after death. New Zealand’s latest attempt to find the appropriate balance takes the form of the Human Tissue Act 2008, which aims to increase organ availability by rationalising the existing consent requirements. In this article, we present a case for further reform.

CONSENT REQUIREMENTS AS A CONSTRAINT ON ORGAN AVAILABILITY

By international standards, transplantable organs are scarce in New Zealand. In 2006, the country had the lowest rate of deceased donor organ retrievals (6.0 per million per year, 25 retrievals) of any of the OECD nations collecting accurate transplantation statistics. Between January 2003 and December 2008, there were never more than 40 retrievals in a single year. The rate of live organ donation over the same time period has stayed relatively static. To give an idea of the demand for organs, as of mid-May 2007 there were 530 people waiting for a kidney, three waiting for a kidney and pancreas, two waiting for a heart, three waiting for lungs and 19 waiting for a liver (personal communication). Not included in these numbers are the many individuals who have been assessed for possible organ transplantation but have not met the necessarily strict criteria. More efficient use of organs (for example split liver transplantation) has offset some of the shortfall but the waiting lists for kidneys and to a lesser extent livers continue to grow (personal communication). The gap between organs sought and organs available is projected to widen in coming years.
Several factors have contributed to this organ scarcity. On the demand side, eligibility criteria have broadened in response to the improving outcomes of transplantation procedures while rates of organ failure, especially due to diabetes, have been increasing. On the availability side, there is some indication that the absolute number of brain deaths has decreased over the last decade, possibly due to prevention of accidents and better hospital care.1,2 A further constraint to organ availability is New Zealand’s system of consent; organs are taken for transplantation only if the deceased expressed no objection to organ removal and the family consents to it. Obtaining consent from the family is not required by law, but is accepted as good medical practice.

Intensivists from Auckland and Wellington set out to quantify the reasons for the shortfall in organs by conducting a study of all intensive care unit (ICU) deaths between 1 April 1999 and 31 March 2000 (unpublished research). During this period there were 1404 deaths in the 31 national ICUs. Two hundred and thirty four patients were ventilated with bilaterally fixed pupils and 116 of these were declared brain dead. The coroner ruled out organ donation in three cases and medical contraindications excluded nine more. This left 104 potential donors. For a variety of reasons (perceived medical contraindications (n=6), spontaneous refusal (n=5), collapse of the circulation prior to request (n=4), denial that death had occurred (n=4) and others (n=16)), the families of 35 of these potential organ donors were not asked about organ donation. Sixty-nine families were asked and 38 consented (55%). Organ procurement began in 36 cases. In New Zealand, organs from a single deceased donor may be transplanted into up to eight living recipients. Assuming that an average of three organs from each donor are eventually transplanted, the absence of family consent may have prevented 93 potentially life-saving procedures during this year-long period (5-year survival for organ recipients currently ranges from approximately 55% for lungs to around 89% for livers).1
These findings suggest that reform of the consent system for deceased donor organ donation has the potential to save lives. Of course, there may be significant scope to increase organ availability without altering the consent arrangements – for example, through public education or changes in infrastructure. But regardless of what other measures are adopted, consent requirements for deceased donor organ procurement will remain a constraint on organ availability. We confine ourselves to the question of what those requirements should be.

**THE HUMAN TISSUE ACT 2008**

In 2008, the New Zealand Government introduced new consent arrangements for post-death organ donation. These were informed by an earlier Ministry of Health review of policy relating to human tissue. The new requirements, set out in the Human Tissue Act 2008, permit transplantation where the deceased either opts on to an organ donation register before death, or consents via a nominated representative after death. The family will no longer have a right of veto in such cases. Where the deceased does not consent in either of these ways, consent from a family member, and normally the family as a whole, will still be required.

We support the direction of these changes, and concur with the implied view that the family should not be allowed to over-ride an individual’s desire to donate. However the reforms do not, in our view, go far enough. The new arrangements still include a strong consent requirement: organs will be taken only if consent is obtained from either the deceased or the family. But lack of consent is not necessarily a good justification for retaining organs. Of course, in some cases, individuals and their families will refuse to consent because they have a strong preference for non-donation, perhaps based on deeply held religious, cultural or moral beliefs or on strong emotional aversions. For example, some Māori believe that removing parts of a dead body affects the wellbeing both of the ūpāpaku (dead body) and the whānau (extended family). Burial is often regarded as a way of returning a person to their
ancestors or tūrangawaewae (‘place to stand’), and failing to bury a body whole may thus be seen as breaking a natural and sacred cycle of life. Some Māori may therefore be strongly opposed to retrieval of organs. We do not claim that organs should be removed in such cases.

However, lack of consent will not always reflect such strong views. Indeed, survey evidence from the United States indicates that, in that country at least, a substantial proportion of those who have not consented to post-death organ removal would be willing for their organs to be removed. This suggests that many individuals remain off the organ donation register because (i) though they would like to become donors, they lack the motivation to formally record this wish; (ii) they have no well-thought-out position on whether they would like to become donors (perhaps because they are reluctant to contemplate this rather morbid question); or (iii) they have a mild preference against becoming a donor. Many families may also withhold consent on the basis of a mild preference, or simply because they are faced with a seemingly intractable dilemma, and non-donation seems to be the ‘default’ option – a perception which the consent requirement obviously encourages. We do not believe that lack of motivation, reluctance to contemplate death, mild preferences or resorting to a ‘default position’ should be allowed to prevent life-saving transplants. In our view, organs should be transplanted in the absence of consent from either the deceased or the family, provided that there is also no significant dissent – provided, that is, that there is no more than a mild preference against organ retrieval.

DEVIATION FROM THE STANDARD MEDICAL CONSENT MODEL

Before offering our positive arguments for this view, we should deal with one obvious objection to it: that enacting it would leave organ donation policy out of line with the standard informed consent model employed elsewhere in medical practice.
One concern underlying this objection may be that loosening the consent requirements for deceased donor organ procurement would encourage the doctors involved in organ procurement to loosen their consent practices in other areas. This is a legitimate concern, but it could easily be avoided, for example, by leaving organ donation consent discussions in the hands of specialised counsellors.

Alternatively, the concern may be that it is logically or morally inconsistent to adopt one consent framework for organ donation policy and another framework elsewhere within medicine. But it is not at all clear that this is so. After all, most of medical practice is concerned with the treatment of living persons, whereas post-death organ procurement is not. Plausibly, people have stronger claims to determine how their living bodies are treated than to determine how their bodies are treated after death. Both our current, living bodies and our future, dead ones have special symbolic significance for us. But our living bodies and body parts also have an obvious practical significance: we depend on their integrity for our ongoing survival and happiness. Arguably, it is on the basis of this practical significance that we have such strong claims to determine what is done to our living bodies.

AN ANALOGY WITH CORONIAL POST-MORTEMS

Of course, individuals do have some moral claim to determine how their bodies are treated after death. Families may also have such claims in respect of their loved ones. But these claims to 'bodily' determination need not amount to absolute rights – claims that cannot be outweighed by competing considerations. In the area of organ donation policy, claims to bodily determination are the pre-eminent consideration: they are allowed to prevent life-saving organ transplants even in cases where there was at most a mild objection to such
transplantation. However, other areas of public policy are less sensitive to these claims. Consider current policy on coronial post-mortems.

In New Zealand, coroners may order a pathologist to perform a post-mortem on a body without the consent of the family or the prior consent of the deceased. Coroners must take into account the wishes of the deceased person’s family, and may take into account the prior wishes of the deceased, but in cases of suspicious death they are not obliged to comply with those wishes. They may order post-mortems even in the face of dissent from the deceased or the family. This is, moreover, a well-accepted policy; most people seem to agree that in allowing coroners to take into account the views of the deceased and the family, current post-mortem policy gives appropriate recognition to individual and family claims to bodily determination.

In our view, if post-mortem policy gives appropriate weight to these claims – which we agree that it does – then the new Human Tissue Act gives them too much weight. Under that legislation, as currently, objections of the deceased and the family will not merely be taken into account, they will be allowed to dictate whether organ transplantation can proceed. Moreover, this would be true even if the objection amounted to no more than a mild preference that organs be left in place. There are, however, good reasons to think that cases of organ procurement and of post-mortem examination should be treated similarly. Compare the two cases. Both involve compromising the integrity of the deceased person’s body. But both do this in order to achieve important public goods: the advancement of forensic investigations, and the saving of lives through transplantation. Indeed, if saving lives is more morally urgent than advancing forensic investigations (which we believe is the case), it would seem that public policy on organ donation should, if anything, take less account of claims to bodily determination than policy on post-mortem examinations.
It might be objected that there is an important disanalogy between the cases of coronial post-mortem and deceased donor organ transplantation – one that relates to the amount of tissue removed from the body in each case. The objection cannot be that organ transplantation requires the removal of tissue whereas post-mortems do not, for the law permits body parts and tissues to be taken, and even destroyed, in the course of a coronial post-mortem. Nor can the objection be that organ donation involves the removal of some types of tissue that could not be removed in post-mortems, for policy on coronial post-mortems does not restrict the types of tissue that may be removed. Rather, the objection would have to be that organ transplantation will typically require that a greater amount of tissue is removed.

It is not immediately clear, however, why this difference should be important. Perhaps removing and distributing major body parts might be thought to harm the deceased in a way that performing a post-mortem does not. However, this line of argument does not look very promising. It is controversial whether dead people can be harmed. Some commentators do believe that people can have interests which extend beyond their own deaths, and that anything that sets back these interests may qualify as a harm. But we are aware of no principled account of posthumous harms according to which having a larger amount of tissue removed from one’s body should be considered a greater harm than having a smaller amount removed.

Alternatively, it might be objected that, contrary to our above suggestion, the forensic goals of coronial post-mortems are more important than the medical aims of organ transplantation. After all, failing to convict criminals can lead to widespread public fear and justified indignation. However, as noted above, transplanting organs from a single deceased donor can save several lives – as many as eight. It seems unlikely to us that conducting a single coronial post-mortem would, at least in typical cases, achieve any similarly important benefit given that success or failure in a single forensic investigation will have little effect on public fear.
and indignation, and performing a post-mortem investigation will be decisive in securing a
conviction only in a minority of cases.

**SAVING LIVES AT SIGNIFICANT COST**

The analogy with post-mortems suggests that our consent arrangements for deceased donor
organ transplantation give too much weight to the views of the family and the deceased.
Another way of making this point would be to say that they give too little weight to the
objective of saving lives.

Saving lives is not normally regarded as an all-conquering moral consideration. We would
not, for example, contemplate any relaxation of the consent requirements for *living* donor
organ donation, even though this could save lives. However, as we noted above, there are
reasons for thinking that we have weaker claims over our dead bodies than over our living
ones, so little follows from this for *deceased* donor organ donation.

There are, of course, also less dramatic cases in which the imperative to save lives is over-
ridden by other considerations. We allow people to drive cars at 50 kilometres per hour in
built up areas even though we could plausibly save many lives by prohibiting this. On the
other hand, in many areas of medicine, we are prepared to tolerate very significant costs in
order to save lives. For example, most of us would think it justified to terminate a late
pregnancy to save the mother’s life, even though this clearly over-rides the foetus’s moral
claim not to be killed. Similarly, most of us would think it justified to inform a patient’s
sexual partner that the patient is HIV positive, though this may over-ride the patient’s claim to
confidentiality.
These are difficult cases. But ultimately, many would be prepared to over-ride what are normally taken to be quite powerful moral claims in order to save lives. Yet in the sphere of organ donation, where the potential benefits are similar, we do not tolerate even a minor impingement on individual and family claims to bodily determination. These claims are held to be absolutely decisive, even when based only on mild preferences.

**TWO POLICY OPTIONS**

We believe, then, that the proposed consent arrangements for deceased donor organ transplantation get the balance between saving lives and respecting bodily determination wrong. A better balance would, we think, be achieved by allowing organ transplantation to proceed in the absence of consent from the family and the deceased, provided that there is also no significant dissent. (Note that this approach would still give greater recognition to bodily determination than current policy on post-mortems, which allows even significant dissent to be over-ridden.) But how can those who significantly dissent be distinguished from those who do not?

One possibility is suggested by the analogy with coronial post-mortems. When an intensive care unit identifies a deceased person potentially suitable for organ donation, and that person appears on the organ donation register, organs could be retrieved for transplantation under the new Human Tissue Act. But where the person does not appear on the register, a coroner-like agent could make a (rapid) decision on whether organs should be removed. This agent would take into account any evidence on the views of the deceased regarding organ donation. She would also listen to the views of the family. But the decision on whether organs may be taken would be hers, and she would be instructed to permit transplantation unless she judges that there was or is significant dissent – that is, more than a mild preference against organ procurement – from either the deceased or the family. The agent could be issued with specific
instructions on how to assess the strength of a preference (we leave it as an open question what these should be). Alternatively, this could be left up to the individual agent. We note that in the case of coronial post-mortems, coroners are given great freedom to determine how to take dissent into account, and we are not aware of this having caused undue problems.

As well as easing constraints on organ availability, this system would have a further advantage: it would avoid placing the burden of a weighty decision on a grieving family that may neither wish nor be well placed to bear it – final responsibility for taking that decision would now lie with the coroner-like agent. The presence of the coroner-like agent would also mitigate the conflicting pressures on intensive care physicians. Under the current system, intensivists, who must normally put their own patients first, are charged with requesting organs on the behalf of potential recipients who are not their patients. A coroner-like agent, having no particular allegiance either to potential donors or potential recipients, would be in a less conflicted position. The task of the coroner-like agent would nevertheless clearly be a difficult one; significant dissent and mere non-consent will often be difficult to distinguish. But we see little reason to suppose that this task would be any more difficult than that already undertaken by coroners in deciding whether to order post-mortems.

Another policy option would combine the above model with a variant of the opt-out approach that is already in place in several European countries, including France, Belgium, Spain and Austria. In opt-out systems, all people are classified as organ donors unless they actively opt-out of this category by formally recording an objection. By never seeking active consent from individuals prior to death, opt-out systems ensure that people are classed as donors unless they have objections strong enough to motivate opting out. (In many opt-out systems, organ procurement can also proceed in the absence of active consent from the family, though here practices vary widely.)
Opt-out systems have typically been well-accepted by the public and the medical profession, and in scientific comparisons have generally been shown to increase organ availability, even after adjustment for potential confounders such as public support for organ donation. In some cases, the apparent effects of policy change are dramatic. In Belgium, the organ donation rate rose by 55% within five years of the introduction of an opt-out system, whereas in Denmark, it fell by 50% following a move from opt-out to opt-in.

Our favoured version of the opt-out system would incorporate the changes proposed in the Human Tissue Act 2008 by including an opt-in component. It would also retain the coroner-like agent for cases in which the deceased neither opted in nor opted out. Individuals would have three choices. They could (i) opt in, by joining the organ donation register, thus making organ removal automatic, (ii) opt out, thus ruling out organ removal, or (iii) neither opt in nor opt out in which case a coroner-like agent would assess whether there is significant dissent from the family and decide accordingly.

Figure 1 summarises the approach captured by both of our proposed policy options.
We believe that either of our proposed systems would increase the availability of transplantable organs. In Belgium, only 2% of the population had opted out of organ donation ten years after the system was introduced: in that country at least, the proportion of the population that significantly dissents to deceased donor organ procurement appears to be very small.22 Similar results have been found in other countries operating opt-out systems.15,25 These findings cannot be extrapolated straightforwardly to New Zealand, where opposition to organ removal would more than likely be greater due to cultural and religious factors, particularly the spiritual beliefs of Māori and Pacific people.11 But it nevertheless seems likely that rates of significant dissent would be substantially lower than rates of non-consent.

CONCLUSION

New Zealand’s stringent consent requirements for deceased donor organ procurement constrain the availability of potentially life-saving organs. The proposals contained within the Human Tissue Act 2008 may increase organ availability to some extent. However, we support a further move to a coroner-like system that would distinguish between the absence of consent and the presence of significant dissent, or to a variant of the opt-out approach. We believe that, if coupled with culturally aware education programmes based on sound social research, either system could provide a greater pool of organs for transplantation in a manner acceptable to wider society.
ACKNOWLEDGEMENTS

We would like to thank Janice Langlands (Organ Donation New Zealand), for providing helpful information. We would also like to thank Drs. Chris Duffy, Andrew Moore, and MaryLeigh Moore and two anonymous reviewers for their comments on drafts of this article. Thomas Douglas received funding from Christ Church College, University of Oxford and Nicholas Douglas received funding from the Rhodes Trust.
REFERENCES


