

People die while we argue about the wrong thing: The problem of organ donation

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The recent debate about organ donation was surprisingly heated. People complained about a 'nanny state' infringing on their post-mortem rights; some threatened to tear up their donor cards if the proposed change to an 'opt-out' system went ahead. 'Opt out' means presumed consent, or a legal system in which people no longer have to actively join the organ donor register (ODR) in order to become donors. Everyone is automatically treated as a potential donor, unless they actively opt-out. Supporters of presumed consent propose this system as a means of increasing the number of organs available for transplantation. Opponents say it violates their right to their body after their death. The government has recently appointed a taskforce to examine the proposed change to a presumed consent system, triggering a public debate about the pros and cons of presumed versus informed consent.

This public debate, for all the strong emotions it arouses, has focused on the wrong issues. Moving to a presumed consent system is unlikely to produce the sorely-needed increase in the number of organs available for transplantation. The empirical evidence shows that opt-in (informed consent) and opt-out (presumed consent) typically yield similar results in terms of number of organs procured, so a change to opt-out will not *in itself* solve the problem of organ shortage. Instead of arguing about the type of legal system that ought to be in place, we should focus on investment in infrastructure, public education and organisational change, as these are the measures that will in fact increase the number of organs available for life-saving transplantation.

What are the stakes?

At present, there are 263 people in the UK waiting for lung transplantation. 245 people are waiting for a liver and 6,789 waiting for kidneys. Some of these people will die while on the waiting list. Transplantation is an option of last resort for patients with heart, liver and lung disease but it is the most effective and preferred method of treatment for end-stage kidney failure. In the case of lungs, for example, a person is only referred for a transplant when they have a life expectancy of 12-18 months. If the waiting list is, on average, longer than that, that person is likely to die. At present, median average waiting times for a transplant are 406 days for lungs, 103 days for hearts, 841 days for kidneys, 95 days for livers and 265 days for a kidney and pancreas. (Source: UK Transplant)

However, according to UK Transplant, transplants in the UK are successful. A year after surgery, over 90% of patients who have received kidney transplants are functioning well; the corresponding figures for liver and heart are 86% and 84% respectively. Lung and heart-lung transplants are less successful, with one-year survival in the region of 75%.

What are we arguing about?

A legal framework for organ donation has two essential variables:

1. The type of consent required from the individual in order to procure their organs.

Presumed consent, or 'opt-out', means that people are presumed to have consented for their organs to be used in transplantation unless they actively opt out.

Informed consent, or 'opt-in', means that people must actively consent (by joining the NHS ODR or carrying a donor card) for their organs to be used for transplantation.

2. The weight, if any, given to the wishes of the deceased's family. If the family is given legal power, they can override the deceased's presumed or informed wish to donate their organs. Alternatively, the family may have no say, and procurement could, in principle, proceed even if the family objects. *De facto* this rarely happens.

So there are four options:

1. Presumed consent with family veto.

2. Presumed consent without family veto.

3. Informed consent with family veto (meaning that the family can override the deceased's *explicit* wishes).

4. Informed consent without family veto.

Option 3 was the status quo in the UK for many years. However, a legal change introduced by the Human Tissue Act (which came into effect in September 2006) brought in option 4, so if a person is on the ODR, their organs can now legally be procured even if their family objects. This legal change was made in response to the finding that over 40% of families refuse to donate their relative's organs, even though many of the deceased carried donor cards or had joined the ODR. Despite the change in legislation, procurement teams are very sensitive to families' wishes and are unlikely to override them, even though legally entitled to. Thus, the change in legislation has, in practice, made little difference to donation rates.

One point is immediately clear: if the family's wishes always override the deceased's wishes, whether legally or *de facto*, it makes no difference whether a system of informed or presumed consent is in place. If the family has the final say, it doesn't matter what the deceased wanted when they were alive; so whether we have an opt-in or an opt-out system will make little difference. This is the first reason we are arguing about the wrong thing.

Moreover, while advocates of presumed consent are routinely criticised for seeking to impose a 'nanny state', the parallel danger of a 'nanny family' – a person's explicit wishes being overridden by their family – has escaped criticism almost entirely. As Lynne Holt, of the Heart and Lung Transplantation Unit at Newcastle's Freeman Hospital, says: "Donor transplant coordinators still seek the consent of the next of kin. In practice we have not gone against the wishes of the donor

family purely because of the fallout that may happen if we did. In the UK, the wishes of the living continue to override the wishes of the dead. This obviously reduces the number of organs offered, which results in the number of deaths on the transplant waiting lists”

Families are much less likely to agree to their loved one’s organs being used for transplantation if they only learn that they had joined the ODR at the moment of death. Laura Siminoff found that if the potential donor’s family knew in advance that their relative carried a donor card, the consent rate was near 90%. But if the family only found out during the request process, about 40% refused consent.¹ According to UK Transplant, up to 40% per cent of families in the UK object to organs being used for transplantation, but when presented with evidence of the deceased’s wishes to donate, refusal rates are much lower. This is the crucial reason why we should discuss our wishes with our families.

Let us now look at the difference in numbers of organs procured between countries that have informed vs. presumed consent systems. Sociologist Kieran Healy compared procurement rates in countries like Switzerland and Sweden, which have presumed consent laws, to countries that have informed consent laws, like the UK and Germany.² He found that the difference in procurement rates was small. This suggests that the proposed change to presumed consent will not *on its own* solve the crisis of organ shortage, and will in fact make only a small difference to the current situation. What, then, would bring about an improvement in the status quo?

The Spanish model

The most successful organ procurement program was designed in Spain, and has also been implemented in Italy. Nurses and doctors are specially trained and placed in every hospital in the country. This guarantees that when a potential donor is identified, specialists are able to discuss donation with the family and spend time with them during the difficult period preceding their loved one’s death. Moreover, they offer support even if the family decides not to donate the organs. The Spanish invested heavily to make their organ procurement program a success: new jobs, specialist training and a public education campaign. The average waiting time for a lung in Spain is substantially shorter than in the UK; over 50% of those waiting for lungs will receive their life-saving organs within 6 months and 80% within a year. In 2007, 185 lung transplants took place in Spain, compared to 115 in the UK, despite Spain’s population being 25% smaller. (Source: Organización Nacional de Transplantes, Spain and UK Transplant). The rate of organ donation in Spain went from 14 donors per million population (pmp) in 1991 to 34.6 donors pmp in recent years. A similar pattern can be seen in Italy, where rates of donation rose dramatically from about 5 pmp in 1991 to nearly 20 pmp in 2002.

¹ L. Siminoff et al. “Factors influencing families’ consent for donation of solid organs for transplantation”. *Journal of American Medical Association* 71 (2001), 286.

² K. Healy, “Do presumed-consent laws raise organ procurement rates?”. *DePaul Law Review* 55 (2005-6), 1017-43.

Why is there such a shortage of organs?

In the UK, 90% of people agree that organ donation is a good thing. But only 25% have registered as organ donors. When I ask people why they haven't signed the register, a common reply is 'I haven't got round to it' or 'I don't know how I feel about it'. I am certain that if they or a member of their family needed an organ, they would know very quickly how they feel about it. They would know what it is like to sit there, day after day, and see a loved one suffer, waste away and then die, not because of lack of resources, operation theatres or medical know-how. Not because of a shortage of drugs, funds or post-operative care. Simply because of a shortage of organs, which arises because nothing akin to the Spanish model has been put in place in the UK.

Potential organ donors are usually quite young and have often suffered an accident or brain haemorrhage so their death is sudden and unexpected. When a bewildered, grief-stricken relative sits by their loved one's bed and a doctor requests permission to use the organs for transplantation, it is not surprising that many refuse. The family is likely to be suffering from a great deal of emotional stress, to be traumatised by grief and not thinking clearly. They may want to prevent their loved one from any more medical procedures, or may be horrified at the thought of organs being retrieved from their child or wife's body. Their reaction is understandable.

That is why UK Transplant is investing in public education and in strengthening the existing network of transplant coordinators. Otherwise, we will be missing important opportunities for procurement. Furthermore, the Spanish experience shows that asking the family's consent at the right time, in the right way, can help them give meaning to their loved one's death. They find solace in the thought that other families have been spared a similar fate thanks to their generosity.

Even when a potential donor has been identified, the family's consent obtained and the procurement undertaken, there is still a chance that the organs may be unsuitable. If the donor has been on a ventilator or a life-support machine, their organs may be damaged. Even if the organs are in good condition, a transplant can only take place if the donor and recipient have matching blood groups and tissue types, and are approximately the same size. The recipients, who are themselves very ill, cannot have any infections or be on antibiotics or other drugs. The crucial problem is not just finding the organs but matching them to the right recipient and getting them to the recipient quickly. The complex process of matching a donor to a recipient and getting the recipient to hospital must be done within hours of the donor's death; otherwise, the organs deteriorate and are no longer suitable for transplantation.

So even if that all-important call comes and the ill person goes to hospital and is brought to the operating theatre, they may still find themselves going home without their hoped-for new organ, as there may be a problem that can only be detected once the operation begins. This phenomenon – known as 'the false-alarm' among those on waiting lists – can be psychologically traumatic for those who wait months and years for their call. All these complications mean that it is crucially important to maximise the number of organs donated for transplant. A public education program, designed to teach people about the huge benefits that organ donation may bring, is the first step. This will encourage people to discuss their wishes with their families in advance, so that in the event of a tragic accident, their families are aware that their loved one wished to donate their organs.

Our duty to others

If you have never met someone who is on a waiting list for an organ, I urge you to try to imagine their plight. Here are a few stories of people I know. My friend G has been waiting for a single lung transplant for nearly two years. She suffers from LAM, a rare lung disease that has destroyed her lungs to the extent that she cannot bend down to pick up a piece of paper from the floor. Another woman, A, is in a wheelchair, as her lungs cannot support even the smallest oxygen demand created by walking. She has been waiting for 14 months. Their long and painful wait comes at the end of a prolonged illness; lung transplantation is the option of last resort and offers them their only hope. Another woman who was in a similar position five years ago is now able not only to work and lead a normal life, but even play sports again, thanks to her successful lung transplant. Others who are not as lucky are dying for want of organs.

We should not have the privilege of refusing to engage with such people. Ill people are part of society and as such we have a duty towards them. Just as we have a duty to help someone who has fallen down in the street or suffered a heart attack, so we have a duty to help those who are languishing helplessly on the transplant waiting lists. How can we help? By joining the NHS ODR and making sure our families know that we wish to donate our organs. By doing this we can also help our families, who, if the occasion arises, will have to make the decision whether to donate. By making our wishes known we not only ensure that our wishes are respected, but also that our families are not burdened by having to make the decision for us.

We should not be allowed, because of psychological squeamishness or sheer thoughtlessness, to avoid the issue. Not deciding, not bothering to figure out how you feel about organ donation, is an omission to act whose consequences are dire. If we think that we have moral duties towards other people, then surely the duty to at least consider organ donation is among them. Failure to do so may cost someone their life, as they await an organ that may not become available in time.

Moreover, each of us is more likely to need an organ than to actually become a donor. More people desperately require an organ than become donors themselves. When discussing organ donation, people mainly consider the question whether they want to donate, whereas empirically they are more likely to be on the receiving end. So it is rational for each of us to join the ODR and to agree to donate our relative's organs, if we are ever in that situation.

What is the aim of the debate?

Before we plunge into a lengthy and ineffective public debate about the ethics of presumed consent, we should stop and ask ourselves: what are we trying to achieve? Is our aim a just and effective healthcare system that offers each and every one of us, lucky or unlucky, a chance to live a good life? Or is our aim to argue endlessly about some putative right that dead people have to organs they no longer need? It seems obvious, upon learning the facts, that the shortage of organs is an unnecessary folly inflicting needless suffering on thousands of people who live intolerable lives. Should we let people who could be saved suffer premature deaths while we get caught up in abstract philosophical discussions?

This is not to say that the proposed change to presumed consent is not a step in the right direction. As Healy suggests, presumed consent laws can “function as a signalling device to the population in general and next of kin in particular... Donation is still a choice, but saying ‘yes’ is assumed to be the standard option, rather than a special decision for which consent must be specially sought” (p.1028). But legal change is only part of the picture. Due attention must be given to organisational structures which play a decisive role in the success of any organ donation programme, and yet have been largely neglected by the public debate.

Until such a change comes, the right thing to do is to sit down today – not later, next month or next year – and ask yourself if you would wish to receive an organ transplant if it was necessary to save your life. Presuming your answer is ‘yes’, then you should tell your family what your wishes are and sign on to the ODR without delay. Just as we wouldn’t deny anyone life-saving medication or treatment, nor should we deny them the chance of a better life through organ transplantation.