
1. Preface

This book presents the proceedings of the third ELPAT congress held in Rotterdam, The Netherlands, April 20-23, 2013.

ELPAT stands for the Ethical, Legal and Psychosocial Aspects of Transplantation and is part of ESOT, the European Society for Organ Transplantation.

The theme chosen for the third ELPAT congress was 'Global Issues, Local Solutions' and we thank the European Commission and The Transplantation Society for making this congress possible.

We were happy to welcome 360 delegates from 52 countries and we were able to accommodate 215 presentations.

Free communications, focus sessions and interactive workshops were organized according to the seven ELPAT working groups: Deceased Donation, Legal Boundaries, Living Donation, Organ Tourism, Trade and Trafficking, Children, Psychological Care and Public Issues.

During the congress the ELPAT Public Issues working group launched the first book on 'Public Engagement in Organ Donation' while a special session was organized on the project 'Living Organ Donation in Europe (EULOD)', a Coordination Action, funded by the European Commission.

As can be seen from the content of this book all ELPAT topics have been explored and discussed. It is a reflection of the continuous debate on the Ethical, Legal and Psychosocial Aspects of Transplantation.

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2. Global Issues, Local Solutions/ Global Outreach

Personal rights and the acquisition of organs

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Organs for transplantation are an effective form of treatment for organ failure.¹ At least in rich countries, they are also cost-effective. Public providers and private insurers are willing to fund more transplants than there are organs available. The major policy problem for transplantation is a shortage of its raw material, not a shortage of money. Acquiring the organs faces an ethical problem too: organs for transplant come from other people, dead or alive.

Here are some of the familiar ethical problems. When organs are taken from the dead, should the dead have to give consent, or should their families, or both, or neither? (In other words, these are questions about presumed consent and opt-in systems, about the family's power of veto, and about the conscription of organs.) When organs are taken from living people, who thereby risk physical and psychological harm, who should be allowed to donate – only competent adults with close ties, or also strangers, or people who are on the margins of competence or even incompetent? Under what conditions, if any, should the organs of either the living or the dead be allowed to be bought? Any answers to these questions must take account of the, perhaps competing, interests of the people whose organs they are or were, the interests of their families, the needs of those with organ failure, the interests of the health professionals involved, and the feelings and beliefs of the wider society.

This paper tries to show that the key way to think through the ethical problems is in terms of people's rights to determine what to do with their own bodies and, in particular, to veto bodily interference. According to this paper:

- (1) people do have rights over their bodies and these rights extend past their deaths;
- (2) thinking about what these rights require is the basis for the correct, or at least defensible, answers to many of transplantation's ethical problems; and
- (3) while rights may not always be the only basis for the correct answers they are in the case of the conscription of organs after death.

Consider these three examples, which make a number of points about rights:

- (1) Suppose a man promises to donate a kidney to his son, and then refuses. With certain further details, we would be justified in holding this man's refusal to be morally wrong. Suppose too that society finds his behaviour repugnant. Nonetheless, few would say this man should be forced to submit to the removal of his kidney for transplant into his son.
- (2) Suppose a competent woman refuses the removal of a cancerous kidney even though removal is necessary to save her life. It is widely accepted that her kidney may not be removed when she refuses even when it is in her interests to have the kidney removed.

¹ A note on references: this paper brings into focus more clearly a theme in my book *Ethics and the Acquisition of Organs* (Oxford: Clarendon Press, 2011) and that book has all the references anyone could reasonably want for the claims made here. I would like this paper to be pleasantly readable so I have not cluttered it up with notes.

- (3) Consider some reasons for compulsorily taking the second kidneys of living people to allocate to those with renal failure. The loss to the person of one kidney would likely be outweighed by the gain to the recipient who has no functioning kidney; conscription would reduce the inequality between those with two kidneys and those with none; and conscription would help the worst off, since those with no kidneys are worse off than those with two, and worse off than those with two would be after one is taken off them. Yet virtually no one suggests conscripting so much as blood let alone kidneys. Our body parts may not be conscripted even when conscription would do more good than harm and have apparently fairer outcomes.

Assuming our intuitions in these cases are right, we can conclude that people have rights and these rights are of considerable weight. In the first case, the right outweighs the needs of the son and society's feelings of repugnance; in the second, the rights outweigh the woman's own biological interests; and in the third, the right outweighs the greater needs of others. Rights can thus tell us how to decide between competing goods and claims.

However, while we may accept the intuitive conclusions in these three examples, what more can we learn? The examples are concerned with living people's rights, so no conclusion can immediately be drawn about retrieval from the dead. And the examples involve bodily integrity; they are cases of vetoing retrieval. So no conclusion can immediately be drawn about whether people should be allowed to donate or sell their organs, since disallowing would not infringe upon the integrity of their bodies.

I think people do have rights that extend past their deaths. And I think people's rights over their bodies go beyond the right to veto retrieval. I think people have rights of 'personal sovereignty' that includes a right to make consensual agreements with other people. Of course, I cannot persuade you in the space I have that we have such rights. What the rest of this paper does is indicate how a rights approach can help with some of the problems of transplantation and also to show why, in the case of organ conscription, thinking about rights is not just a help but essential.

Here is an indication of how a rights approach can help. Take some of the questions about taking organs from living people. Who should be allowed to donate or sell what organs? To what extent should people be allowed to act in ways that other people think likely to be against their interests? If people have rights of personal sovereignty, then a strong initial case is made against using legal coercion to prevent them freely selling their own body parts. The case is not decisive, but that they have rights will help us evaluate the considerations on the other side. For instance, it is sometimes argued that permitting sale is contrary to the value of altruism, but if people have rights to sell, that seems to rule out using legal coercion to uphold altruism.

Consider also the role of the family in retrieval from the dead. Virtually everywhere, the family have a *de facto* power to veto retrieval no matter how strongly the deceased had wanted to donate, and some people think this power violates the right of the deceased. But even assuming that people have rights past death, the right will not be a right to donate; it will only be a right to offer. A refusal of a clinically unsuitable organ does not infringe on a right. I have elsewhere argued that where the family's *de facto* power is the result of a justified wish by transplant professionals to avoid bad publicity, the power does not infringe on the right of the deceased. Whether or not the argument is correct, the point is that we can make progress with this ethical problem by sharpening our thoughts about the rights people have. The sharpening also helps with the choice between opt in and opt out systems of retrieval. Some people think an opt out system is wrong because organs should not be taken without the consent of the deceased. We can evaluate that argument by thinking through whether it is always the infringement of a right to interfere with a person's body without

that person's consent. It is not, for instance, in the case of emergency treatment of unconscious patients.

These last few examples involve rights that supposedly extend past death. The challenge is to explain how a right could extend past death or, equivalently, how taking organs after death from a person opposed could infringe on her right given that she no longer exists. In essence, my argument is that one can have interests in the success of one's goals and their success does not depend only on what happens within one's own biological life. Events after death can affect one's interests too. People's interests in what happens to their bodies are generally of great weight, and should be protected by a right. The interest in what happens to one's organs is an interest in one's body and it can be affected by what happens after death, so that interest is protected by a right. However, no one should be persuaded by the argument when it is set out in only a few sentences. All of those claims made are eminently disputable and require a lot of work in ethics and metaphysics to make them persuasive.

As a rule, it is best to avoid difficult foundational work in ethics and metaphysics if we are trying to solve practical problems. We can all agree, for instance, on the importance of informed consent in medicine without worrying about whether we are consequentialists, or Kantians, or virtue ethicists or something else. If different foundations have the same practical answers, why try to decide between the foundations? Many writers on transplantation ethics have followed the generally sensible rule, noting (although with some inaccuracy) how societies respect wills and taking that as the non-foundational basis for following people's wishes about their organs. In fact, the arguments above, which tried to show that the family veto and opt out systems need not infringe on the rights of the deceased, do not actually presuppose rights past death. They could be taken as arguing that even if the dead have rights, their rights would not be infringed upon. Obviously one could reach the same conclusion if the dead did not have rights at all. So they are cases where (if I am right) we can be helped with transplantation ethics by thinking through rights without having to decide whether anyone has the rights. But not every question can be answered in this non-committal way. The widespread rejection of conscription can only be based on an individual right to veto the retrieval of one's organ after death and such a right cannot avoid the foundational challenge.

Although, as far as I know, every jurisdiction with a transplant program gives individuals the legal power to veto the retrieval of their organs, some writers say they should not have such a power. According to these writers, dead people do not need the organs while living people with organ failure need them so greatly that organs should be routinely taken even from people who opposed retrieval – in other words, the policy for organ acquisition should be conscription.

Here is one way to see the force of the greatest needs argument for conscription. Suppose a pilot knows his plane will crash and he can only steer it either into the paediatric wing of a hospital or into the mortuary, which at that time contains only dead people. Surely we would think he should steer the plane into the mortuary and we would not change our minds if it turned out that the people in the mortuary had all wanted to be buried intact while no one in the paediatric wing cared about their remains. In other words, when it is a choice between life and respect for posthumous wishes, life should win. By parallel, should we not then conscript organs regardless of the wishes of the dead?

A conscription policy does not follow directly from the crash-into-the-mortuary-conclusion. Perhaps conscription would not actually work to get more organs. But suppose it would. What could be so important about the individual's power of veto that it should override the needs of potential recipients? One answer is: that individuals have rights over their bodies that extend past their deaths

and these rights override the greater good that would be done if their organs were taken. Remember the earlier cases of rights against organ retrieval. At least for people whose organs could be taken while they were alive, their rights outweighed the greater good that could be done from organ reallocation. If people's rights extend past death, they could be the basis for a veto.

On the avoid-foundational-challenges approach, the argument I favour should be taken as just one potential reason for the individual veto and against conscription. Put another way, the metaphysics is dispensable. But I think the other supposed foundations for the individual veto either (a) do not support the individual veto but something else or (b) are not alternatives to the rights approach or (c) are not strong enough to support the veto against the claims of potential recipients.

Take an argument against conscription built on the needs of surviving family members. Some writers believe conscription to be wrong because it would cause psychological harm to the deceased's family. But no argument based on the family supports the individual veto in cases where the individual had no family or where the family want to donate and the individual did not. Nor, I think, are the interests of the deceased's family strong enough to outweigh the needs of potential recipients especially when these are added to the interests of *their* families in their health and survival.

Take an argument that says people with strong religious objections should not have their organs taken because of the importance of religious freedom. This is one of those arguments that turns out not to be an alternative to the rights approach as we see when we ask: 'Whose religious objections rule out retrieval?' The answer is not just anyone's. My religious objection to some stranger's organ donation is simply irrelevant. The point is that religious freedom is at best insufficient until one has established on some other ground who is entitled to control what happens to the body.

Take an argument based on the fears of the living, for instance one that says if conscription were known to occur, living people would be upset and worried. This is one of those arguments simply not up to the job of supporting the individual veto against conscription (as before, assuming conscription would get more organs than a system with an individual veto). Some people are frightened by the very existence of transplant programs, even ones that scrupulously respect individual wishes, because they believe doctors hasten death to get more organs. Such fears are not good enough reasons to close down the transplant programs. It is more important to treat organ failure than to allay fears. So, if conscription would provide more organs how could it be ruled out just because of any extra fear it creates?

The thesis that individual rights extend past death is not just one basis among several for the rejection of conscription; it is the only defensible basis. But this thesis itself needs foundations to explain how people's interests can be affected by posthumous events. Even then, it may be argued that posthumous rights are not absolute and the benefits of conscription outweigh respect for the rights. Such an argument deserves careful consideration, more indeed than it usually gets. But, to return to the point of this paper, it provides another example of how debates over transplantation ethics are advanced by thinking through individual rights and their limits.

Organ donation and transplantation in emerging economies

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Abstract

Developing countries with emerging economies have low transplant (< 10 pmp) and still lower deceased donation (DD) rates (< 5 pmp) as compared to countries with developed economies with (> 40 pmp) transplant rate and (> 30 pmp) DD rates respectively. The reason for this disparity is not entirely economic development. Inadequate transplant facilities in government sector hospital, high costs in private centres and inaccessibility due to rural dwelling renders the majority of the population disfranchised from transplantation. Moreover DD rates are low due to a lack of awareness about transplantation in general and brain death in particular, negative interpretation of religious rulings and cultural perspectives concerning the dead body. Organ trade in many countries created mistrust of the professionals and affects transplant negatively. Availability of vendor kidneys reduced altruistic donation and in many countries delayed enactment of transplantation laws. Our institute created a model of community-government partnership to provide free dialysis and transplantation to the disfranchised populations with life long follow-up and medication. This model overcame major hurdles and brought forward living donors and initiated deceased donor program. The way forward in emerging economies is to provide transplantation to those who need it irrespective of cast, color or creed keeping transparency and equity in the forefront.

Introduction

Globally seen transplantation is the preferred treatment for end stage organ failure (ESOF) as it provides high quality life years to patients. Unfortunately, there are still many limitations to access transplantation, especially in emerging economies, and as a result transplant rates per million population (pmp) vary from 1.0 pmp in Africa to 46.6 pmp in America [1]. These transplantation rates with both living and deceased organ donors also equate with the human development index (HDI), a composite of life expectancy, education and purchasing power parity. High HDI countries have donation rates from > 30 to up to 60 pmp while low HDI countries have < 10 pmp [2]. In this report we highlight the hurdles that stand in the way of establishing viable deceased organ donation and transplant programmes in emerging economies. These include economics, social and cultural issues. Religious impediments, professional attitudes and transplant commercialism are other reasons.

Economic issues

The Global Observatory on organ donation and transplantation has grouped countries according to transplant rates, while the World Health Organization (WHO) has divided the world into 6

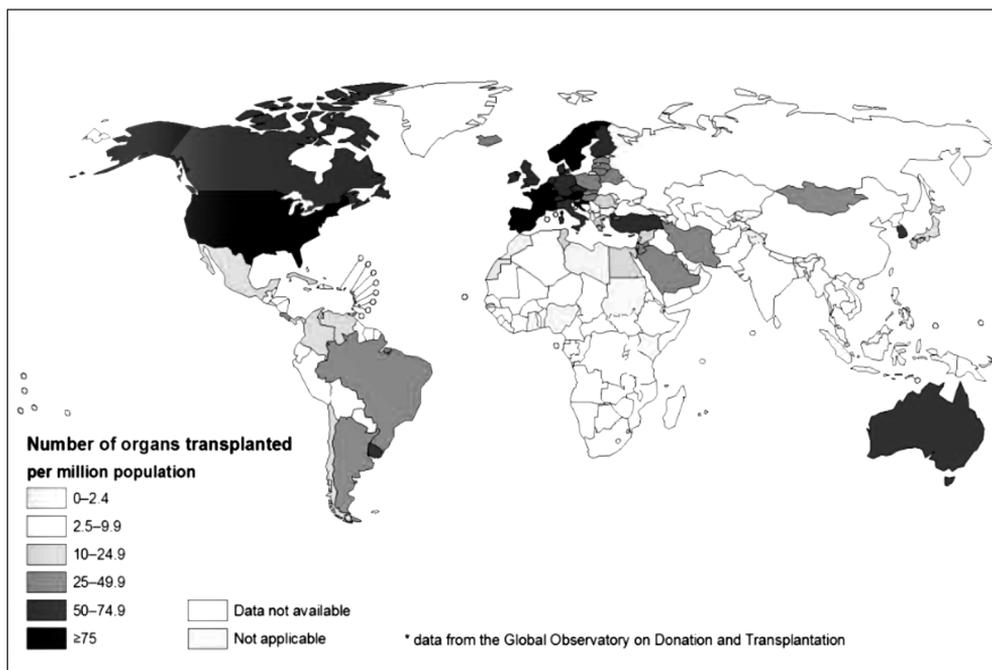


Figure 1: Global activities of solid organ transplants in 2011

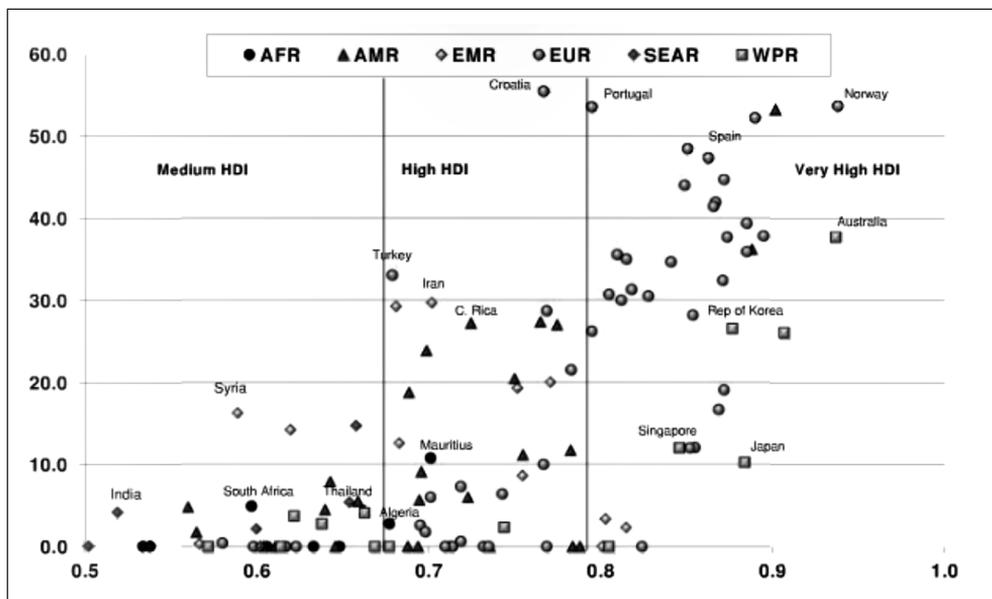


Figure 2: Number of deceased and living donor kidney transplants in World Health Organization Member States in 2010, correlated with Human Development Index