



XENOTRANSPLANTATION

The Foundation held a lecture and dinner discussion on “Science, Society & Xenotransplantation” on 22 February 2000 at the Royal Society. The event was sponsored by the Foundation’s Shared Sponsorship Scheme (Comino Foundation, Esso Petroleum Co Ltd and Kobe Steel Europe Ltd). The Rt Hon The Lord Jenkin of Roding was in the chair. The speakers were Dr David White, Director, Research and Development, Imutran Ltd, Professor John Harris, Institute of Medicine, Law & Bioethics, University of Manchester, and The Rt Revd Lord Habgood, Chairman, UK Xenotransplantation Interim Regulatory Authority.

TRANSPLANTATION AND THE DUTY TO OTHERS

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Summary: Professor Harris examined a wide spectrum of moral, ethical and scientific questions relating to transplantation, bearing in mind the fact that many thousands of people worldwide died annually for want of donor organs. Lord Habgood outlined the functions of the UK Xenotransplantation Interim Regulatory Authority and the criteria by which applications for clinical trials should be assessed. He said the need for xenotransplantation might be a temporary expedient if the possibility of growing cloned human organs came to fruition.

Introduction The questions I wish to try to answer this evening are of fundamental importance for the ethics of human tissue and organ transplantation. They are particular forms of the very fundamental and central question about our obligations to others.

Our task then is to try to decide what, if any, obligations we have to participate in medical research and what, if any, obligations we have to make available to others’ human tissue and organs for transplantation? I shall suggest a binding ethical principle. It is that we have an obligation to participate in research and to contribute to other public goods, which may preserve lives. The scope of this principle and exceptions to it will be matters for discussion.



Lord Butterworth, President of the Foundation (right), talks to The Rt Revd Peter Hullah, Bishop of Ramsbury, at the event.

Immediately, another warning needs to be issued about moral principles. Moral principles are not just plucked from the air, but neither are they derived from unassailable premises or immutable absolutes. They articulate central elements of a shared morality. Like the ‘ten commandments’ and other sacred and venerable articulations of central beliefs, they remind us of that morality and our commitment to it and, like the famous commandments, they require interpretation.¹ However, they also differ from commandments and other theologically derived texts in important ways. Unlike commandments, they do not attempt self-justification, they do not purport to explain why they ought to be accepted. So, when we articulate a moral principle we are reminding ourselves of what we believe to be an important part of the morality we accept. We should follow the principle because we accept the morality, but the principle cannot give us reasons for accepting the morality. When we encounter a principle we need first to reflect on our morality to see whether and how the principle fits with it. We then need to explore the consequences of accepting the principle to see whether we can adhere to it consistently with others’ moral beliefs we share and wish to retain. If the principle can be applied consistently with our general morality, well and good; if not, we have to choose whether to abandon the principle or abandon the elements of our morality which are not consistent with it.²

Ethics based medicine

Before doing so we must examine another assumption that has been made. I’m assuming that medical ethics is part of ethics more generally and that what it is ethical to do to and for people within a health care system, or ‘clinically’, or in research settings, is constrained by our general morality. The assumption being made, then, is that the delivery of health care, both individually and within a health care system, is a dimension of our more general obligations to one another and, in particular, that it is entailed by those commitments we have to honour other people’s entitlements to concern, respect and protection. In short, the duties of health care professionals or research scientists, in so far as they are ethical duties, are derived from general morality and are not part of a particular ethics of health care. The ethical dilemmas that arise within a health service may be different from those arising within a prison service for example, but the principles, which inform the resolution of those dilemmas, are drawn from our general morality.

Resistance to this idea often comes from a confusion about the different

sorts of normative systems that operate within any society. Our general morality is just one of the normative systems which operate within society, albeit the one to which all others are answerable. Other general normative systems include the rules governing religious observance, rules of good manners or etiquette, and, of course, the legal system. Then there are the rules of particular professions, occupations, corporations or clubs that are often rather misleadingly referred to as codes of professional ethics or corporate ethics. All or any of these normative systems may enjoin or forbid things in the name of morality, and the operation of these normative systems may generate ethical dilemmas. For example, although it is always wrong (incorrect) to break the law, it is not always morally wrong. The law requires us to drive on the left in the United Kingdom. There is nothing unethical about driving on the right except in so far as it is dangerous (or possibly unfair) to do so where others are conforming to the law. If it is morally wrong to commit murder it is so not because law forbids it, rather the law forbids it because it is morally wrong.

Medical or health care ethics (as opposed to bioethics) may then be construed as the ethical code of a particular profession or professions or of the health care system. So construed it has limited force and will appeal, at most, only to members of those professions or perhaps, more pessimistically, to those who wish to become or continue to be members of those professions. As we shall construe it, however, it is the application of our general morality to the dilemmas of research and of health care more generally.³ Thus construed, research ethics applies as much to research subjects or to patients and their friends and relatives, as it does to researchers, doctors or nurses and it is as concerned with the general obligations of society to carry out research or to provide health care as it is with the duties of researchers or other professionals to deliver it.

Religious and cultural traditions contain elements of all these sorts of normative systems. They have strands, which are more clearly like the rules of a club or a profession. They will also, of course, have important things to say about all the major moral concerns of humankind. However, nothing in any religion or cultural tradition absolves each of us, each member of the religion or cultural tradition for thinking through moral questions for ourselves. There are three main sorts of reason why this must be true and it is worth just noting these before we continue. I will not, of course, have time to develop these points in any great detail or with much sophistication.

1. Ambiguity

Nothing written in a natural language is unambiguous. As William Empson famously remarked “in a sufficiently extended sense any prose statement could be called ambiguous”.⁴ All statements then are not only susceptible to interpretation and qualification, but it is scarcely possible to understand any sophisticated statement without interpretation or gloss. Whether the source of our moral guidance is a self-consciously didactic text like the ten commandments, the universal declaration of human rights or, indeed, this lecture, it will require, at the very least, interpretation and qualification and almost certainly critical evaluation as well.

2. Moral Relativism

Although a certain degree of moral relativism is now regarded as both politically correct and intellectually required, I do not believe there exists a coherent version of moral relativism. If that is, moral relativism is interpreted as rendering a moral system or set of culturally derived values immune from “external”⁵ critical evaluation. There are many reasons that should be persuasive in rejecting moral relativism and I will have time to mention just two. The first is that cultures and religions develop and evolve. There is no major religion which does not have a theological tradition, a tradition of the study and interpretation of religious texts and doctrine. Partially through these traditions, religions and cultures and their values and their morality evolve and develop. At least sometimes religions and cultures change and develop for good reasons, sometimes these changes are even changes for the better. These reasons may be theological, they may sometimes even be logical. However, whatever counts as a good reason for change or development from within a culture and religion will also count as a good reason when voiced from outside the culture or religion. Although, of course, it may seem less appealing when coming from outside. This shows that no religion or culture can be hermetically sealed from outside influence. This, of course, is a relatively weak argument. It only shows that cross-cultural criticism is not necessarily imperialistic, it cannot show that it is never imperialistic. However, there is one other reason as to why moral relativism must be false, and it is our third reason for maintaining that ethics is always a rational, not simply a religious or cultural activity.

3. Ethics and theology are necessarily independent of one another

There is an argument familiar to philosophers and indeed to theologians which seems too clever to be true. However, it has never, so far as I am aware, been refuted. I use Bertrand Russell’s famous formulation of it:

[I]f you are quite sure that there is a difference between right and wrong then you are in this situation: is that difference due to God’s fiat or is it not? If it is due to God’s fiat, then for God Himself there is no difference between right and wrong, and it is no longer a significant statement to say that God is good. If you are going to say, as theologians do, that God is good, you must then say that right and wrong have some meaning, which is independent of God’s fiat. Because God’s fiat’s are good and not bad independently of the mere fact that He made them. If you are going to say that then you will have to say that it is not only through God that right and wrong came into being, but that they are in their essence logically anterior to God.⁶

This argument does not, of course, say anything about the existence of God, nor does it deny his or her goodness. It merely points out that the statements “God is good” and “God is God” have different meanings, if “good” is to have any meaning at all. One of God’s great claims to fame is that he wills the good. It is our ability to reason about the nature of the good independently of God’s fiat, as Russell calls it, that partially accounts for theology and indeed enables us to say, non-vacuously, that God is

good. For if we believe that God only wills the good, then if we can establish what is good, we have reason to choose between rival interpretations of God's will.

With this preamble in mind we must now turn to the question of the scope and limits of the obligation to make available donor tissue and organs.

The Ethics of Organ Transplants

Organ and tissue transplants present a complex set of problems to health professionals. There will be concern for two groups of patients and their friends and families: the potential organ donors and also the potential recipients. Each claim our concern, respect and protection.

However, the ethics and law on organ transplants must first be seen in context. It is difficult to estimate how many people die prematurely for want of donor organs. Archbishop Trevor Huddleston, writing in the nineteenth edition of the Journal of the British Kidney Patients Association, quoted the transplant advisor of Papworth Hospital as suggesting that in the case of heart transplants, "around 25% of people on the waiting list will die before an organ becomes available". It is difficult to know how this would translate for other organs. In the UK, with a current waiting list of over 5000 for kidneys alone, it is likely that at least one thousand people die annually for want of donor organs. And things are likely to get worse. Recent figures issued by the Royal College of Surgeons indicate that there are currently "less than half the number of registered donors needed to meet demand and that 30% of relatives of people who have died refuse to give permission for their organs to be removed".⁷

But even these disturbing figures need to be placed in a global context. The waiting lists in international terms represent a major catastrophe on a global scale. There are around 100,000 people currently needing organ transplants in India and only about 3,000 transplants are performed annually – most of the "donors" are live and are female.⁸ Around 61,000 are waiting for transplants in the United States, of which 40,000 are waiting for kidneys. In Italy, 30,000 people are on dialysis. In the United States in 1997, 20,045 transplants were performed. More donations that year were cadaveric than living. The most recent death figures that I have, from 1996 in the United States, show that of the 72,386 patients on the waiting list at some point during that year, 4,022 died; 45% of those were kidney patients.⁹

How can we stem the massive loss of life and the human misery that this represents? I shall briefly suggest two ways.

The first is the automatic availability of all cadaver organs – a measure which I first advocated publicly over sixteen years ago.¹⁰

The second is a restricted market in live organs. Again, this is a measure which I defended in detail in 1992.¹¹

Cadaver donation

What would a decent public policy on cadaver donation look like? At the moment we have an ‘opting in’ system (donor cards) and there has been some pressure for us to move to an ‘opting out’ system which is sometimes called ‘presumed consent’. In this latter case organs would be available for transplantation unless the potential donor had registered his or her objections to donation prior to death. Both of these systems give central place to the individual’s right to determine what happens to his or her body after death. I propose to challenge this assumption. I will suggest that consent is inappropriate as a ‘gate-keeper’ for cadaver donations. Before doing so, however, we should note that those in favour of presumed consent as the way forward have already dispensed altogether with the notion of consent.

Problematic consent to treatment

Because there are so many cases in health care practice which necessitate touching patients in circumstances where their consent cannot be obtained and where knowledge of their wishes is absent, the law has contrived various fictional consents to protect well-intentioned practitioners from the guilt of unlawful conduct. The moral necessity of obtaining a valid consent, where this can be obtained, does not require further discussion. To violate the bodily integrity of persons who reject such violation is a form of tyranny and should be accepted and treated as such. We must, however, look more closely at those cases where consent or its refusal is problematic, and at the fictionalised consents that are often manufactured in these circumstances.

There are a number of instances in health care where the patients’ consent is appealed to and used, where her actual consent is unobtainable. These are circumstances in which the patient is either unconscious or unable to process the information required to give a valid consent, or is temporarily or permanently lacking the relevant capacity to consent. In such cases terms like ‘proxy consent’, ‘substituted judgement’, ‘presumed consent’ or even ‘retrospective consent’ are used to justify treating a patient. This is, of course, also the case with presumed consent for cadaver donation.

Provision for these sorts of ‘consents’ is endorsed by most of the leading international protocols on research. For example, the Declaration of Helsinki provides that “Where physical or mental incapacity makes it impossible to obtain informed consent, or when the subject is a minor, permission from the responsible relative replaces that of the subject...”¹² . The other leading source of guidelines in this field are the International Ethics Guidelines for Biomedical Research Involving Human Subjects, prepared by the Council for International Organisations of Medical Sciences (CIOMS) in collaboration with the World Health Organisation (WHO). Their Guideline 1 states: “...in the case of an individual who is not capable of giving informed consent, the proxy consent of a properly authorised representative” must be obtained.¹³

However, not only are these all fictions, but they totally fail to be justifications for treating the patient in the absence of actual or prior consent.

Here, of course, we shall be advancing a thesis that runs counter to much contemporary thinking on consent which seems at home with attributing consent to individuals who are totally unaware that they are supposed to be consenting or were unaware at the time the consent is operative (as in the case of retrospective consent).

The reason why it is right to do what presumed consent or substituted judgement seems to suggest in these cases, is simply because treating the patient in the proposed ways is in his best interests and to fail to treat him would be deliberately to harm him. It is the principle that we should do no harm that justifies treating the patient in particular ways. The justification for treatment is not that the patient consented, nor that he would have, nor that it is safe to presume that he would have, nor that he will when he regains consciousness or competence, but simply that it is the right thing to do, and it is right precisely because it is in his best interests. That it is the 'best interests' test that is operative is shown by the fact that we do not presume consent to things that are not in the patient's best interests, even where it is clear that he would have consented. We do not usually mutilate patients who have expressed strong requests for mutilating operations, for example. We do not, except where we believe it to be in the patients' best interests, amputate healthy limbs of patients suffering Body Dysmorphic Disorder.¹⁴ Nor do we infuse heavy smokers with cigarette smoke while they are unconscious, even where it is reasonable to suppose they would have consented, and patients are often denied access to alcoholic beverages or cigarettes, even when they specifically request them.

It is widely held that not only should we not harm people who do not want to be harmed, we also should not harm even those who do want to be harmed, and that this is sufficient reason not to withhold treatment, the absence of which would harm. This raises the question of the right to harm oneself, which I have no space to discuss further here.

Not only do we not need the concept of implied or assumed or proxy consent, because it literally does no work, we do not need it because it misleads us as to the character and meaning of our actions. The nineteenth century English philosopher Jeremy Bentham was rightly scathing of fictional consents, he remarked:

In English law, fiction is a syphilis, which runs in every vein, and carries into every part of the system the principle of rottenness ... Fiction of use to justice? Exactly as swindling is to trade ... It affords presumptive and conclusive evidence of moral turpitude in those by whom it was invented and first employed.¹⁵

So where, in medical contexts, we act in the best interests of patients who cannot consent, we do so, I suggest, because we rightly believe we should not harm those in our care or because what is proposed is clearly the right thing to do and not because some irrelevant person or the law has constructed a consent. This does not, of course, help with the vexed problem of who is and who is not competent to consent, but it does explain the justification for intervening in the lives or with the dead bodies of those we are satisfied are not able to give the consents that would otherwise be required.

It is understandable that people might prefer not to have their bodies taken apart and the tissue and organs used after their deaths. It is equally understandable when people prefer that their relatives' and friends' bodies are undisturbed after death. There are, of course, also such things as persisting, or critical interests, which survive death, and one such might be the interest in what happens to one's body after death.

The crucial issue is not whether or not there are such interests or preferences, but what weight to give them and whether, all things considered, using the organs of the dead to save the lives of the living is the right thing to do.

Perhaps the first thing to say is that a *feeling* that one's own organs or those of loved ones should not be used, or that our bodies should not be 'desecrated' after death, is not necessarily a moral feeling.¹⁶ However, even if such feelings were to be given moral weight, they would have to be balanced against the powerful moral reasons for using bodily products in contravention of those feelings. If we can save or prolong the lives of living people and must do so at the expense of the sensibilities of others, there seem to be powerful arguments that we should. For the alternative involves the equivalent of sacrificing people's lives so that others will simply *feel* better or not feel so bad.

Where, as at present, most societies have a voluntary system for donation of bodily products, it is important not to alienate the potential donors or frighten them off altogether. Equally, it is important to be sensitive to the sensibilities of those, relatives perhaps, whose permission will be necessary if body products are to be made available to therapy or research.

It is widely agreed that if the permission of the relatives of the deceased is necessary, then the deathbed is neither the most considerate, nor the most opportune, place to ask for it. Nor is it exactly tactful to ask a dying individual if they wouldn't mind parting with those parts of themselves that will be surplus to requirements in the near future, that is of course with every bit of themselves.

A question we should press here is: would it be wrong of the relatives, or indeed of a moribund individual, to refuse to donate cadaver organs? One answer to this question is suggested by the fact that if it is clear that for want of an organ, or some bone marrow an individual will die, then the failure to give those bodily products or permit them to be given will result in death.¹⁷

All the moral concern of our society has so far been focused on the dead (who don't need it) and their friends and relatives. But there are two separate sets of individuals who have moral claims upon us, not just one. There is the deceased individual and her friends and relatives on the one hand, and the potential organ or tissue recipient and her friends and relatives on the other. Both have claims upon us; neither's claim has obvious a priori priority. If we weigh the damage to the sensibilities of the relatives of cadaver donors if their wishes are overridden against the damage done to would-be recipients if they fail to get the organs they need to keep them alive, where should the balance of our moral concern lie?

If we address this question seriously we must think what each group stands to lose. The cadaver donor stands to lose very little. She is dead and past being harmed, except in the relatively trivial sense in which people possess interests that persist beyond their death and which can in some sense be harmed.¹⁸ Shakespeare, of course, had it both ways. Mark Anthony, in Julius Caesar, certainly talks as if the dead can be wronged: "I rather choose / to wrong the dead, to wrong myself and you / Than I will wrong such honourable men".¹⁹ But in Macbeth Shakespeare takes a different view: Macbeth himself, talking of the murder of Duncan whom he has "sent to peace", says: "Duncan is in his grave; / After life's fitful fever he sleeps well; / not steel, nor poison, / Malice domestic, foreign levy, nothing / Can touch him further".²⁰ I myself incline more to Macbeth's view. For although the dead may indeed be wronged in a sense, it is, necessarily in a very attenuated sense when compared with the wrong that may be done to the living.²¹

We must remember that while the organ donor may have a posthumous preference frustrated, and her friends and relatives may be distressed and upset, the potential organ recipient stands to lose her very life.

(To be continued in the next issue, Autumn 2000.)

1 Does the proscription on killing include animals and plants? Are some commandments more important than others? Is the prohibition against coveting neighbours' oxen as important as that against coveting neighbours' wives?

2 This does not, of course, purport to be a complete account of either morality or moral reasoning.

3 I have argued this point in greater detail in my *The Value of Life*. Routledge & Kegan Paul 1985, Ch. 3.

4 William Empson *Seven Types of Ambiguity*. Chatto & Windus Ltd, 1930 (Revised Edition 1970), Ch. 1.

5 This term also requires much interpretation.

6 Bertrand Russell 'Why I am not a Christian' from *Why I am not a Christian and other essays*. George Allen & Unwin, London, 1957.

7 [Http://news.bbc.co.uk/1/hi/english/health/newsid_281000/281404.stm](http://news.bbc.co.uk/1/hi/english/health/newsid_281000/281404.stm)

8 From oral presentation by Ajay Sharma given at the "Multicultural Ethical Issues in Transplantation Conference", University of Manchester, 21st-22nd February 1999.

9 The United States figures are from the United Network of Organ Sharing (www.unos.org).

10 "In vitro Fertilisation: The Ethical Issues", *The Philosophical Quarterly*, July 1983. 217-238. And *The Value of Life*. Routledge & Kegan Paul, 1985. Ch. 6.

11 See Wonderwoman & Superman. Oxford University Press, Oxford, 1992. Chs. 5 & 6.

12 World Medical Association Declaration of Helsinki as amended by the 48th General Assembly, October 1996. Basic Principle 11.

13 International Ethics Guidelines for Biomedical Research Involving Human Subjects, prepared by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO). Geneva 1993.

14 Indeed, doctors at Falkirk and District Royal Infirmary were recently much criticised for so doing.
(http://news.bbc.co.uk/1/hi/english/uk/scotland/newsid_625000/625680.stm).

15 Hillel Steiner A Theory of Rights. Blackwell, Oxford, 1994. p. 258.

16 See my The Value of Life, Routledge, London, 1989. Ch. 6, and my 'Embryos & Hedgehogs' in Anthony Dyson and John Harris (eds) Experiments on Embryos,