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Authorisation, altruism and compulsion in the organ donation debate

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ABSTRACT

The report from the Organ Donation Taskforce looking at the potential impact of an opt-out system for deceased donor organ donation in the UK, published in November 2008, is probably the most comprehensive and systematic inquiry to date into the issues and considerations which might affect the availability of deceased donor organs for clinical transplantation. By the end of a thorough and transparent process, a clear consensus was reached. The taskforce rejected the idea of an opt-out system.

In this article we acknowledge the life saving potential of organ transplants and seek to highlight the difficulties that arise when the issue of organ shortage competes with concerns over choice and authorisation in the context of deceased donor organ donation.

INTRODUCTION

The report from the Organ Donation Taskforce¹ looking at the potential impact of an opt-out system for deceased donor organ donation in the UK, published in November 2008, is probably the most comprehensive and systematic inquiry to date into the issues and considerations which might affect the availability of deceased donor organs for clinical transplantation.

By the end of a thorough and transparent process, a clear consensus was reached. The taskforce rejected the idea of an opt-out system. The main reasons for this rejection were scepticism about the extent to which an opt-out system might improve the supply of donor organs and faith that putting in place the measures they recommended in their report *Organs for transplant*, published in January 2008,² will result in a 50% increase in deceased donor organ availability by 2013. They did however suggest that opt-out systems should be reviewed in five years time in light of the success achieved.

Importantly the taskforce was unanimous in its support for organ transplantation and their report makes clear their commitment to increasing organ supply and increasing public awareness of the need to eradicate the terrible loss of life that results from a scarcity of donor organs year upon year.

Where ends are agreed, the only questions left are those of means. In the context of deceased donor organ donation means are multi-faceted; they must, for instance, take account of social forces and political ideas. But this does not mean

that they are fixed concepts, impervious to rational criticism. If the consequences of adopting such means are devastating, negotiating their permissible limits and alternatives is advisable and required for all persons of good will. In this article, our focus lies with examining the legitimacy, or otherwise, of persisting with a framework of deceased donation based upon a model of consent, and highlighting the difficulties that arise when the issue of organ shortage competes with concerns over choice and authorisation in the context of deceased donor organ donation. However, before examining theoretical reasons for accepting, or rejecting, an opt-out system of deceased-donor organ donation and assessing alternative models, we would like to acknowledge the important role that healthcare professionals, patients and their families play in the organ donation pathway. The taskforce's concerns over the potential negative implications and damage to the 'vital relationship of trust' between clinicians caring for people at the end of life, their patients and their families, should not be underestimated and merit detailed consideration in, and of, their own right (UK Department of Health publication, section 1.9).¹

TRANSPLANTS SAVE LIVES

In the UK between 1 April 2008 and 31 March 2009, the number of people who had their lives saved or improved by an organ transplant was 3513. Of these, 2552 received an organ from a deceased donor and a further 961 received an organ from a living donor.ⁱ In the USA, 23 846 transplants were performed between January and December 2009 from 12 185 donors.ⁱⁱ In the UK, over the last decade, the number of potential recipients on the transplant list has increased year upon year. The number of deceased organ donors however has remained relatively static. The number of living donor transplants has increased considerably over recent years, partly as a response to the shortage of deceased donor organs available

ⁱ Figures from NHS Blood and Transplant (NHSBT), Organ Donation and Transplantation Directorate: <http://www.nhsbt.nhs.uk> formerly known as UK Transplant (UKT): <http://www.uktransplant.org.uk> http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/2008_09/tx_activity_report_2009_uk_summary.pdf

ⁱⁱ Figures from The United Network for Organ Sharing (UNOS): <http://www.unos.org>

for transplantation.ⁱⁱⁱ However for many, such as individuals who are awaiting a heart transplant, living donor transplantation is not a therapeutic option.

ORGAN SHORTAGE COSTS LIVES

As of 22 January 2010, 7970 people are still waiting for transplants in the UK, and there are 105 333 waiting list transplant candidates in the USA.^{iv} As of 31 December 2008 there are 15 397 people registered on the Eurotransplant waiting list.^v According to data from the United Network for Organ Sharing approximately 10% of all patients on the waiting list for solid organ transplantation die each year without receiving an organ.ⁱⁱ In the year 2008–2009, 448 patients in the UK died while waiting for their transplant.ⁱ In 2008, 1253 people registered on the Eurotransplant waiting list died.^v Organ shortage costs lives.

CHOICE

Choice has come to occupy a curious place in healthcare law and ethics. We are all encouraged to make decisions for ourselves, provided of course that those decisions are made voluntarily on the basis of adequate information and that we have the capacity to make such choices. When these criteria are met individual choice is granted respect, however capricious or irrational it may seem. This is not invariably so, since not all choices need respecting or implementing, especially positive wishes (eg, for medical treatment) which require a resources input. However, respect for an individual's choice about the way in which their life goes is one way in which society can be seen to respect individual autonomy and in turn protect capacity.

Autonomy is the capacity of persons to reflect critically upon their first order preferences, desires, wishes and so forth and the readiness to accept or attempt to change these in the light of higher-order preferences and values. By exercising such a capacity, persons define their nature, give meaning to their lives and take responsibility for the kind of person they are.^{3 4} The value that one individual places on activities and goals does not automatically harmonise with the goals and aspirations of another. Values may and do conflict. The variety of the human condition is infinite. But because, and in so far as, I am autonomous, I am free to choose the way in which I live my life.

Systems of deceased donor organ donation based upon individual choice are anomalous in this regard. Death is not an event in life. We do not live to survive death.⁵ When I am dead I have lost the capacity that it is the point of autonomy and the law to protect. I am no longer able to think critically about preferences, desires or wishes. I am no longer able to make choices. 'I' no longer exist. It is neither accident, nor oversight, that offences against the person do not apply to the deceased.

ⁱⁱⁱ Figures from NHSBT and UNOS. A summary of transplant activity 2005–2006 produced by UK Transplant Statistics and Audit Directorate documents that in that year in the UK the number of living kidney donors rose from 475 (in 2004–2005) to 590, an increase of 24%. In 2006–2007 the number of living kidney donors rose once again to 690, an increase of 17%. In 2007–2008 there were 829 living donor kidney transplants. Living donor kidney transplants now represent more than one in three of all kidney transplants. http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports.jsp/ukt/transplant_activity_uk_2005-2006_v2.pdf http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/transplant_activity_uk_2006-2007.pdf [http://www.organdonation.nhs.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/transplant_activity_uk_2007-2008.pdf](http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/transplant_activity_uk_2007-2008.pdf)

^{iv} Figures from NHSBT and UNOS

^v Figures from Eurotransplant International Foundation: <http://www.eurotransplant.nl> http://www.eurotransplant.nl/files/annual_report/AR2008_def.pdf

Death, however, holds a powerfully important symbolic place in many people's lives; for some so much so, that death is inextricably linked to and gives meaning to the value of their life.^{6 7} Indeed some would argue that respecting the living means respecting the dead too.⁸ In their report, the Organ Donation Taskforce Ethics Working Group acknowledged that, although

there is no possibility of harm to the donor, because they are already dead, and therefore incapable of being harmed one might still be able to do wrong to a person after they have died. ... [W]rongs that have been done to a person in life are not cancelled out by their death, so any wrongs committed during a donation process remain morally significant even after the donor is dead.

Ethics Working Group Report, Annex D, p3.¹

Whether or not we agree with this tenet, it is nonetheless the case that it is afforded a privileged position in law. The autonomous wishes of a person expressed while alive, concerning an event in death, are recognised by the Human Tissue act (2004) (hereafter the 2004 act).^{vi}

Thus, as far as the law is concerned, while I am alive, I am free to exert control over whether or not parts of my body may be taken from me upon my death for medical and/or scientific purposes scheduled in the 2004 act.^{vii} In the context of deceased donor organ donation then, a decision of mine not to consent to such an activity prohibits that activity after my death. This freedom, however, is not reflected in all other areas of determination by the living of posthumous events. The rest of the 'estate' of a deceased, for instance, is subject to death duties and other taxation from time to time and is challengeable in the courts. Indeed there are many reasons to think of the corporeal estate in terms similar to real and personal property over which the deceased has a powerful influence but not a decisive say.⁹

Whatever account of the importance or symbolism of death we choose to uphold, it is imperative that we acknowledge the unique context and possibility that organ donation and transplantation presents to us. Transplants save lives. *But for the donated organ the 'life-saving', or 'quality of life saving' transplant would not occur.*^{viii} If we are not prepared to concede that freedom is worthless to those who cannot make use of it, to those for instance who are dead, we must at the very least be prepared to consider whether deceased donor organ donation represents a set of circumstances in which curtailment of individual freedom is legitimate in the interest of the common good and more crucially of the personal survival of other citizens. If we choose not to curtail an individual's freedom, while they are alive, concerning an event in death, we must be able to reconcile to ourselves and make clear why one individual's freedom to exert control over their body posthumously (which must inevitably decay and 'turn to dust'), for medical or scientific reasons scheduled in the 2004 act, is more important than another's life.

The devastating consequences of organ shortage alone mean that we cannot remain absolutely free. We must give up some of

^{vi} The current opt-in system of deceased donor organ donation in the UK entitles individuals to agree to or refuse to consent to organ donation after death. "Appropriate consent" requirements are detailed in section 3(6) of The Human Tissue Act 2004.

^{vii} As Grubb explains however, the law is solely concerned with the 'taking' rather than the 'use' of extra-corporeal organs or tissue. Property law would have something to say about subsequent 'use' and 'control'. See Grubb A, 'I, Me, Mine': Bodies, Parts and Property, *Medical Law International* 3, 299. See also Beylveled D and Brownsword R, My Body, My Body Parts, My Property *Health Care Analysis* 8: 87–99, 2000.

^{viii} Stem Cell Science may in due course change this, but for present purposes this holds true.

our liberty to save the lives of others, and this necessity is not a new form of taxation: the Factory Acts (and all safety legislation), and Jury service are familiar examples. Individual choice, freedom or liberty must be weighed against the claims of those many others waiting for a transplant, who also value their lives and whose lives are of the highest value that morality recognises. The value of an organ to one who has, say, end-stage heart failure, is the value of life; the value that person accords to their own life. But what is the value of an organ to one who cannot make good use of it?

AUTHORISATION

The 2004 act requires explicit or 'appropriate consent'. In the context of a debate about deceased organ donation, the presumption of consent, regardless of whether we operate an opt-in or an opt-out system, is problematic. For instance, as a matter of law, it is not usually possible to assume consent from silence or a failure to object to treatment. If, therefore, the issue of presumed consent was put on the basis of common law of medical consent to treatment, it would necessarily encounter difficulty. Having recognised this, the legal working group of the Organ Donation Taskforce chose to think in terms of 'presumed authorisation' rather than 'presumed consent'. In like vein, the ethics working group also focused on the issue of authorisation.^{ix}

The taskforces report presents us with apparently powerful reasons to endorse authorisation, in particular methods of authorisation that maximise both donation and autonomy.^x For instance when considering the European Convention on Human Rights (ECHR) implications of a presumed consent system, there was consensus by the legal working group, that any system for organ donation which did not provide for the right for individuals to opt-out may be open to a potentially successful challenge. There would, they agreed, be breaches of Articles 8^{xi} and 9^{xii} if the government attempted to make it too administratively difficult for people to opt-out, or did not permit opting out whatsoever. If this is so, then, one might conclude, there must be a good deal of legislation, which by virtue of compelling, or imposing upon, individuals to act in a certain way, is inherently in breach of the ECHR. The legitimacy of these statutes, of which safety legislation is a good example, perhaps derives from the protection of others.

The duty of the state to respect the right to family life and/or the right to religious freedom is likely to be a key issue relating to a possible challenge. Should, for instance, donor families have the opportunity to object in their own right to donation?

^{ix} The term 'authorisation' is used explicitly in the Scottish legislation. See the Human Tissue (Scotland) Act 2006, part 1, sections 6–10 and section 11.

^x The legal working group report (Annex C) documents that their group considered that it may be better in legal terms to think in terms of 'presumed authorisation' rather than 'presumed consent' because in general consent cannot be presumed from silence or a failure to object to treatment.

^{xi} Article 8: 8(1): Everyone has the right to respect for his private and family life, his home and his correspondence. 8(2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

^{xii} Article 9: 9(1) Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice or observance. 9(2) Freedom to manifest one's religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or the protection of the rights and freedoms of others.

Should families be involved to provide evidence of any objection by the deceased? It is clear that family involvement may be invaluable in the donation process. They may, for example, be able to provide the requisite information regarding the potential donor's medical history. But whether this involvement should amount to a legal right of veto is questionable. Allowing family members' own views to trump the consent, presumed or otherwise, of the deceased, completely undermines the purpose that respecting individual autonomy in this context, sets out to achieve. Does family opposition and lack of co-operation provide a legitimate reason to prevent a life saving transplant from taking place? The legal working group agreed that a successful ECHR challenge on the grounds of failure to allow families to impose a decision on organ donation based upon their own views or beliefs (as opposed to the beliefs of the deceased) would be unlikely to be upheld. However, it was felt that, from a pragmatic point of view, '... a degree of flexibility should be built in to the system and guidance on exercising discretion in the face of extreme objection by families would continue to be required' (Legal Working Group Report, Annex C, p5).¹

The expertise and ethics of the legal working group of the Organ Donation Taskforce notwithstanding, it is not clear how either Article 8 or Article 9 could be engaged to support authorisation. Article 8(2) makes it clear that respect for private and family life must give way to 'the protection of health' or 'the protection of the rights and freedoms of others'. When we recall that the individual whose private and family life we are invited to respect no longer exists but those persons whose rights freedom and health are at risk do exist, it seems unequivocal to us that there is no tension between Article 8 of the European Convention and proceeding with methods of organ provision that require no authorisation whatsoever in this context. The same is true of Article 9. The 'right to freedom of thought, conscience and religion' is clearly made in Article 9(2) subject to such limitations 'as are prescribed by law and are necessary ... in the interests of public safety, for the protection of public order, health or morals, or the protection of the rights and freedoms of others'. It is difficult to see how a democratic society faced with a public health and public safety catastrophe which is costing that society thousands of lives would not be justified in limiting both the right to privacy and family life and the right to conscience and religion in order to protect those citizens whose lives are at risk for want of donor organs.

Even if it were possible^{xiii} to extrapolate from a right to a private life that we have a right to privacy after our death it would seem at odds with the spirit of the Convention not to balance this entitlement (should it exist) against the entitlement of others to the right to life. The right to life has to trump Articles 8 and 9 for precisely the same reasons that for instance we do not allow people to kill on the basis of their religion.

Article 2 protects the lives of the living and arguably none of the articles of the ECHR protects the rights of the dead.^{xiv} If authorisation was necessary in order to protect either privacy in death or the freedom of conscience or religion of the deceased then almost no death certificate could ever be issued because the

^{xiii} *Per impossible* as you might think.

^{xiv} Article 2: The right to life. 2(1) Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law. 2 (2) Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary: (a) in defence of any person from unlawful violence; (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; (c) in action lawfully taken for the purpose of quelling a riot or insurrection.

examination carried out by a clinician in order to certify death is never authorised by the deceased.

PRESUMED AUTHORISATION

Two arguments have long since been put forward in support of presumed authorisation. First, the presumption in favour of donation will necessarily result in a greater number of organ transplants. Second, the family will not need to be approached at a time of great emotional distress which in turn will relieve them of the decision-making burden.^{xv} The taskforce found this second argument 'somewhat paternalistic ... at odds with the ethos of today's NHS' (section 8.4)¹ and more than this they felt that there was compelling evidence from donor families that they wanted to be involved in the decision to donate. But if the suggestion is that the ethos of today's NHS is 'moving towards a choice and personalisation agenda ... which gives people a greater sense of control over what happens to them' (section 4.9),¹ the oddity must surely lie with allowing families to overrule or veto an individual's decision to donate. Relieving a family of making a decision that is not theirs to make in any event can hardly be paternalistic. Moreover, the NHS and the government are committed to a wide range of public health measures almost all of which are essentially paternalistic, 'stop-smoking' campaigns at the top of the list. To criticise a suggestion aimed at saving lives, on the grounds that it is 'somewhat paternalistic' seems misplaced, and at odds with the spirit of the NHS which aims to implement life saving measures on the basis of proven benefits, and in the interest of public health and public good. However, this type of criticism powerfully draws attention to the sorts of consequences and (possibly insurmountable) difficulties that arise when a system of welfare regulation, which has at its core, principles of equity and impartial justice, is governed by a model of individual choice, authorisation and autonomy, which inherently relies upon altruism.

Whether or not we agree with a system of presumed authorisation we should not be misled into thinking that a change in the legislation from an opt-in to an opt-out system of deceased organ donation will in itself solve the very problems identified by the taskforce in their report *Organs for transplant*.² The problems identified by the taskforce result from the lack of a structured and systematic approach to organ donation.

Different laws will not necessarily create better systems and it is not clear from the evidence available from European countries for example, that a change in legislation from an opt-in to an opt-out system of deceased organ donation in itself solves the problem of organ shortage.

Deceased donor organ donation in Spain is perhaps the best example of how legislative change in itself does not create an increase in organ donation rates. Spain has the highest rate of deceased donor organ donation in the world. In 1979 'presumed consent' legislation was introduced in Spain. After legislative change was put in place deceased donor organ donation and transplantation at first increased in the 1980s. After a peak of 1182 kidney grafts in 1986, the number then decreased by 20% and the annual number of renal transplants remained at approximately 1000 for the rest of the decade.¹⁰ In 1989, the Organizacion Nacional de Transplantes (ONT) was created. The ONT emphasised the need for one person or group of persons to be responsible for the co-ordination of organ procurement and

transplantation for each potential donor and each hospital. The transplant co-ordinating network was then implemented at three levels: national, regional and local. By 1994 a 50% increase was achieved in the number of kidneys available for transplantation and a more than 100% increase in that of other solid organs.¹¹ More recently, in 1999, Italy introduced 'presumed consent' legislation. At the same time it introduced an organisation much like the Spanish ONT however that organisation is not operational in all regions of Italy. Those regions which have shown a sustained increase in deceased donor activity are the ones that have implemented changes in their infrastructure and organisation of their organ donation programmes.¹² The oft quoted dramatic rise in deceased donor organ donation rates in Tuscany following implementation of the Spanish model is a telling example of just how important a structured and systematic approach to organ donation is.¹³

What is not entirely clear from this empirical evidence is whether legislative change in conjunction with organisational change has been instrumental in the increase in donation rates. Does for instance opt-out legislation affect the way in which relatives of the deceased are approached about, or respond to, the matter of organ donation? The UK is in a unique position in this regard. If a 50% increase in deceased donor organ availability is achieved by 2013 it will be clear that this has been made possible by organisational change alone and credit will be due to those responsible for implementing change. That said, it is difficult to imagine that changing what the public expectations were of conduct in this context does not matter. The taskforce is committed to a public awareness campaign. But nothing gains public awareness more quickly than compulsion or at least the mandating of compulsion. Banning smoking in public places achieved this overnight in the interests of those that might suffer the deleterious effects of passive smoking. But this is an argument to support mandatory donation of organs, not presumed authorisation.

CONCLUSION

The apparent reluctance of our society to endorse a system of deceased donor organ donation based upon anything other than individual choice and authorisation on the grounds that it would represent some form of tyranny is so at odds with our appeal to altruism and the virtue of organ donation, to do that which is for the benefit of others and in the best interests of society as a whole. As such, deceased donor organ donation is a powerful example of the way in which concepts of justice, individual freedom and utility conflict. To the extent that there is incompatibility between these theoretical concepts and deeply held beliefs, there may be no way of adjudicating or resolving their surface disagreements.

If in the final analysis, and on the basis of evidence that will be available to us in 2013, we find that organisational change alone has overcome the shortage of organs available for transplantation, credit will be due to those responsible for implementing change. If, on the other hand, we find that organisational change alone has not overcome the shortage of organs available for transplantation, we must be prepared to concede that deceased donor organ donation represents one set of circumstances in which individualistic considerations must give way to utility in the interests of social and political morality. If we allow personal preference to take priority over the life-saving potential of organ transplants, we must take collective responsibility for the lives that will, as an inevitable consequence, needlessly be lost.

^{xv} As the ethics working group make clear in their report, this case could equally be made for an effective opt-in system or a system of mandated choice, the problem for families being uncertainty and the solution being the system that would best remove this.

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