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Directed organ donation: is the donor the owner?

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Abstract

The issue of directed donation of organs from deceased donors for transplantation has recently risen to the fore, given greater significance by the relatively stagnant rate of deceased donor donation in the UK. Although its status and legitimacy is explicitly recognized across the USA, elsewhere a more cautious, if not entirely negative, stance has been taken. In England, Wales and Northern Ireland, the Human Tissue Act 2004, and in Scotland the Human Tissue (Scotland) Act 2006, are both silent in this regard. Although so-called conditional donation, donation to (or perhaps withheld from) a specific class, has been outlawed as a product of guidance issued by the Secretary of State for Health issued in the wake of the controversial incident occurring in the North of England in 1998, its intended application to 'directed' donation is less certain.

Directed and conditional donations challenge the traditional construct of altruistic donation and impartial (equitable) allocation in a very immediate and striking fashion. They implicitly raise important questions as to whether the body or parts of the body are capable of being owned, and by whom. This paper attempts to explore the notion of donor ownership of body parts and its implications for both directed and conditional donation.

Introduction

Directed donation of deceased donor organs, which involves the direction of an organ (or organs) to a specified person, is distinct from conditional donation, in which donation is

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Other information

Figures are available from UK Transplant (UKT). See http://www.uktransplant.org.uk. In fact there has been an increase in the number of non-heart beating donors, but the number of heart beating donors has decreased. Significantly more transplants are performed from heart beating than non-heart beating donors. See UK Transplant Activity Report 2006–7, http://www.uktransplant.org.uk/ukt/statistics/transplant_activity_report/transplant_activity_report.jsp.

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made to (or perhaps withheld from) a specific class of person. Despite this very clear distinction, at the present time public policy imposes a blanket rejection of any deceased donor organ donation unless it is intended that the organ(s) be distributed through a system of impartial equitable allocation. Directedness of any sort is considered unacceptable. The current policy emerged as a result from an inquiry into an incident in Sheffield where a racist condition was attached to a deceased donor's organ donation.1

The Human Tissue Authority (HTA) response to the very recent case in Bradford draws stark attention to the blanket policy in place. In this case, Rachel Leake, who has end-stage renal failure and is currently on haemodialysis, requested that one of her deceased daughter's kidneys be allocated to her. This, she claimed, would have been her daughter's wish.2 The HTA denied the request. Whether or not we consider the HTA's response to have been appropriate in this particular case, it nonetheless highlights an area of deceased donor organ donation that merits further evaluation.

In this article we explore the notion of donor ownership of body parts and consider the implications that conceiving of human body parts as property have for both directed and conditional donation. Implications for public policy and the current legal framework for deceased donor organ donation are considered.

Provenance

It is often remarked, fairly glibly, that organs are public resources to be distributed by relevant agencies on behalf of the State.3 It is in this context that issues of fairness and efficiency in allocation arise. However, it should be questioned from where such dispositional authority over organs arises. How does the transformation from the 'gift of life' into a public resource occur? The answer may be, perhaps may only be, deducible from the ownership of such human materials. Walter Land once remarked 'The issue of ownership of transplantable organs is of utmost importance since the claim of making allocative decisions may be deduced from the issue of ownership'.4 In like vein, James Childress, Bioethicist and Chairman of the recent Institute of Medicine Report5 on transplantation in the USA, has stated 'It took me some time to discern that our debates about "equitable access" and "equitable allocation" were, in part, debates about who "owns" "donated organs".6 This would appear to be an a priori issue, yet it is one that has attracted fairly modest attention.7

Our reluctance to address the issue of whether our body (or parts thereof) is in fact property has resulted in ambiguous organ donation frameworks. We now find ourselves having to grapple with why one set of circumstances represents a framework in which organ donation can legitimately take place and yet another similar set of circumstances does not, without a clear ethical and legal steer. Whether or not directed donation is legitimate is just one example. As Lindemann Nelson asserts, '… We don't seem to know just what to make of organs for transplant. As things stand, organs aren't fully property as they cannot be sold, nor are they fully public goods, as society may not use them at will. The problems about soliciting directed donation correspond to this ambiguity. Suppose my organs belong to me or to my estate. We would need an argument to block my providing them as gifts to whomever I chose. Suppose, on the other hand, at my death my organs became public goods. Then the appropriate way to distribute them would seem to be via a system of impartial, impersonal justice.'8

Public resource or public custody

Although even directed donation to specific individuals is permissible under US state laws based on versions of the Uniform Anatomical Gift Act,9 the dominant trend domestically

and internationally is that organs from deceased donors should be distributed according to principles of justice and equity, with the emphasis upon those with the greatest medical need.10 If directed or conditional donation were permissible, then inevitably this principle would be compromised in specific instances.

The consequentialist may provide us with good reasons to be a proponent of a system whereby organs from the deceased are considered public goods automatically available for transplantation, directly imported into an impartial equitable system of organ allocation. Any refusal to donate costs lives and it is undoubtedly the case that thousands (probably hundreds of thousands) of individuals have needlessly died an untimely death while waiting for a transplant.11 But if deceased donor organs are *indeed* a societal resource or community 'property' to be allocated according to agreed jurisdictional policies, from where did such property rights derive? If it is not a 'giving' then it is surely a 'taking'; yet we typically deny the latter.

Lloyd Cohen observes in the American context, '… cadaveric organs do not belong to the United Network for Organ Sharing (UNOS). UNOS is given custody and control of organs subject to the conditions placed on those organs by donors.'12 He draws an analogy with charity trustees and argues that they are obliged to handle and deal with trust resources in accordance with the terms of the trust as drawn up by the settler. They are inherently a conditional gift for which transplanters are rightly regarded as 'custodians' or even 'trustees'. Although this fits in well with the notion of a 'gift of an organ' by a deceased person, there is nonetheless considerable negativity surrounding the concept of body ownership, largely as a function of concerns relating to commerce.

Impartial justice and autonomy: two parallel allocation schemes?

It is of course universally the case that living donors may direct donations of organs to individuals with whom one has a relationship of one, sometimes any, type or other. Thus, so it seems, two parallel donation/allocation regimes operate in most jurisdictions, with (in essence) an impartial justice rationale governing deceased donation and a partial autonomy-driven rationale underpinning living donation. It is nonetheless urged that we can properly distinguish deceased and living donation. Kluge, for instance, argues that donations by living persons 'create and sustain intimate personal relationships', and in particular family ties, and constitute exceptions to the general rules of impartial allocation, coupled with the fact that the involvement of society in deceased donation renders such gifts subject to societal standards and rules.13 However, insofar as society is seemingly also 'involved' in living donor transplantation the latter rationale seems tenuous, and the former might suggest that deceased donation to family members at least should also be acceptable. Moreover, the notion that familial donation is a 'deviation' from the norms of allocation is itself contentious.

Even assuming that in the paradigmatic case a specific rationale can be elicited in relation to living donors, the overall picture is now in any event blurred. Anonymous 'altruistic' donation is permitted by strangers in the UK under the 2004 Act subject to HTA approval.14 Under the established scheme, this is not to be directed. Allocation is made to a suitable candidate on the national list of individuals waiting for a deceased donor organ.15 The absence of any pre-existing relationship and the 'spillover' into the province of the deceased allocation system apparently requires that principles of fairness and equity govern the distribution rather than the dispositional powers of individual donors. In the USA, in contrast, there is reluctance to probe into the background to 'supposed' donor/recipient 'pairings' too closely, even though there is a concern that such donors will be directly solicited through the media, accruing a potential advantage to those members of society with

access to such mechanisms (e.g. www.matchingdonors.com). Similarly at ‘arms length’ are cases of paired and pooled (more than two pairs) donation under the 2004 Act, where incompatible donors donate to the ‘scheme’ and a process carried out by UK Transplant to determine the best matchings and pairings.16

The outcome established by all of this is somewhat incongruous. Although we are allowed to decide for ourselves whether or not we want to be organ donors upon our death, in the event that we do, we cannot attach a condition to our ‘gift’ to society. Instead, somehow or another, our donation slips straight into the net of public resource and impartial allocation. If, however, we are alive when we donate, we may legitimately direct our donation (our gift) to someone with whom we hold a relationship of some kind or another. In fact, provided our living donation occurs in the context of a relationship, we can even have our donation directed on our behalf to a stranger and in return we will reap the benefit of seeing the person with whom we have a relationship receive a similar gift from a stranger themselves. If, however, our living donation is not in the context of a relationship of some kind or another, we cannot legitimately direct the very same donation (or gift) to a stranger. Can we really consider that these allocation schemes are legitimately working in parallel when the outcome is as disconsonant as this?

The recent case in Bradford highlights this incongruity. Laura Ashworth, aged 21, tragically died following an asthma attack. Her mother, Rachel Leake, aged 39, has end-stage renal failure secondary to diabetes mellitus. She is currently on haemodialysis and has been reported as being a potential transplant recipient. Laura, who was on the NHS Organ Donor Register, had allegedly told family and friends that she wanted to donate one of her kidneys to her mother. However, at the time of her death she had not begun the formal process of becoming a ‘living donor’ and the HTA, the body responsible for implementing the consent requirements of the Human Tissue Act 2004, refused to let her mother receive one of her organs. Adrian McNeil, chief executive of the HTA, said: ‘the central principle of matching and allocating organs from the deceased is that they are allocated to the person on the UK Transplant waiting list who is in most need and who is the best match with the donor’.17 Of course, had Laura gone through the formal process of living donation and still been alive it would have been considered perfectly legitimate for her to direct the donation of one of her kidneys to her mother.

Legal conundrums

Who owns my body?

The law protects individuals’ rights to control the use of their bodies for medical purposes, even after death.18 It is by virtue of this right that the Human Tissue Act 2004 empowers an individual to appropriately say ‘yes’ or ‘no’ to (consent to or refuse) organ donation. However, the traditional rule has been that the human body cannot be property. At common law it is well-established that there can be no property in a corpse.19 This means that a body or body parts cannot generally be stolen.20 The law does, however, recognize a right to possession of a dead body for burial or cremation, and for certain other purposes and is prepared to protect that right.21 Thus, as Gage J recently asserted, English law is currently uncertain and unclear.22 This is perpetuated by the Human Tissue Act 2004.23 This Act was intended to provide a comprehensive framework for issues relating to the use and storage of bodily material. It, however, focuses on the requirement for consent, rather than the granting (or affirming) of property rights in removed material. Yet the Act is also clear that human material can legitimately become property by ‘the application of human skill’.24 The application of work and skill to parts of the body may invest a person with the right to possess such parts, creating the possibility for a criminal theft of such items to occur.25

The peculiar outcome of this is that although an individual is the only person able to consent to the possibility that her body might be able to become subject to property rights in this context, in the event that it does it is not hers. Although an ingenious means of sometimes protecting the rights of possessors, it is not a convincing framework in the context of organ donation (requisite work and skill may not necessarily even have been carried out) if we persist in conceiving of 'our donation' as 'our gift' to society. Although such a person seemingly acquires proprietary as well as possessory rights by such means, he/she nevertheless cannot 'direct' the use of organs for transplantation him/her self. Transplanters have no power themselves to authorize the use of such organs.

One cannot give what one does not have

What remains unclear, and what the Act unfortunately fails to give guidance on, is whether property rights in human material can become acquired by other means and who has them (i.e. is the 'owner') in such an event. However, gifts are not valid where the donor has no 'disposing power'. One cannot give what one does not have. If instead one advocates the view that the corpse is *res nullius*, but that professionals become entitled to property rights in transplantable parts by virtue of being the first persons to take possession of them – thus converting them into societal resources – one must provide a response to the allegations of arbitrariness and lack of principle that are directed at it.26 Notions of collective property in body parts are anathema to most liberal societies.

The difficulty for many in conceding to the legitimacy of body (or part thereof) ownership arises most obviously as a function of concerns relating to commerce. The view perpetuated by the 2004 Act is that whenever human tissue becomes a property, it may legitimately be traded. Where transplantable material has become a property by 'the application of human skill' it is then excluded from the offence relating to commercial dealings in the statute.27 This improperly conflates property with tradability. One can quite properly and coherently own something that one may nevertheless not trade.28 Without substantive evidence, it does not logically follow, from the possibility of commerciality, that commodification is in fact legitimate nor that it can be properly applied to *all* circumstances within the context of organ donation and transplantation.

Autonomy

Even if one rejects the notion of donor ownership of organs, one can (through a model of consent at least) nonetheless endorse the donor's right to control the use of his or her body parts while either alive or dead. This would reflect individuals' autonomy over their bodies even if not ownership of their bodies. They are the donors to give or otherwise. This appears to be accepted by the primacy afforded to the decisions of the predeceased donor under the 2004 Act, and the 2006 Act in Scotland. While typically the donor's gift is given 'to the transplant patient community as a whole', it arguably raises the possibility of a gift being able to be directed to a specific person instead. Moreover, if we are to persist with a framework of consent as the basis upon which donor organs become available for transplantation then it is imperative that we make clear why, having consented, a person should have greater autonomy over the use of their organs when alive than when dead. If we are unable to provide compelling reasons as to why, we perhaps ought to either concede to a model of property law as the appropriate basis upon which deceased donor organ donation should be legitimate or reconsider the validity of using a model of consent in this context altogether.

Directed and conditional donation

Donee property entitlement: a case of misdirected directed organs

The recent US case of *Colavito29* highlights for some the problems relating to property rights connected to directed donation, potentially generating enforceable property entitlements in specified donees. In that case, a legitimate directed kidney donation to a friend of the deceased was frustrated by the first organ being unsuitable and the second used instead for another patient. Certainly, if directed donation is permissible, specified donees should be able to exercise some claim over the organ(s) concerned apart from where, as in *Colavito* itself, they are not clinically suitable for transplantation into the donee in any event. Thus if, as in that case, there were legitimate reasons (lack of histocompatibility in that instance) for any withholding or re-direction, the action would, as in that case, fail.

Are all directions equal?

The notion that organs are principally for donors to direct or control raises the possibility, for some spectre, of conditional donation based on membership of a class. Indeed, allowing donation subject to any constraint may even be considered as the embodiment of illegitimate discrimination and engender a wholly negative attitude towards organ donation. One need not necessarily conflate directed and conditional donation though. Although UNOS accepts directed donation it rejects the conditional donation of organs for transplant.

However, a blanket or dogmatic approach may not be the most appropriate policy response even in the latter context. While on the one hand we have had an example of a Ku Klux Klan member who would only donate to a white person,30 it was also reported that in the USA a Buddhist monk was only willing to donate a kidney to a stranger not associated with a killing vocation of any type (e.g. hunter, fisherman, military person)31 and a number of strangers have requested that their kidney be given to a sick child. These examples seem poles apart to many. The objectionable feature of conditional donation is arguably its illegitimate treatment of one or more classes of persons, not differential treatment *per se*. Thus, we might, as in Florida, prohibit by law anatomical gifts based on the race, colour, religion, sex, national origin, age, physical handicap, health status, marital or economic status, yet allow other bases for donation.32

Hilhorst urges that we should permit donation to groups that are not ‘suspect’. He states ‘In short, although impartiality will probably be the main feature of a cadaveric allocation scheme, we can and should grant directed donation, when applicable, also in this context’.33 He emphasizes the importance of partial donation to organ donation in general, and notes that one harbours feelings of ‘belonging’ within a community or group, just as much as one feels connectedness to particular individuals. One might then be prepared to admit certain forms of conditional donation where there was no explicit or implicit undesirable discrimination against certain groups within society, i.e. legislate by allowing conditional donation subject to exceptions as opposed to a blanket prohibition.

Public policy

The Report of the Panel *An Investigation into Conditional Donation* in 2000 stated ‘To attach any conditions to a donation is unacceptable, because it offends against the fundamental principle that organs are donated altruistically and should go to patients in the greatest need’.34 Both directed and conditional donation may result in organs being allocated other than by reference to fairness or need, as in the case of living donation. Supporters of this view appear to consider that one buys into the whole package (i.e. allocation according to the public, distribution according to objective criteria), or not at all. Another argument in favour of this view is that if perceived fairness in the organ allocation

system, especially by minority groups, is undermined, this may have a detrimental effect on the organ donation system as a whole. But if we are prepared to implement a system of organ donation and allocation based on the possibility of altruism then we must be prepared to properly consider all of the possibilities that altruism presents to us and we must be able to coherently explain why some altruistic 'gifts' are more equal than others.

Conclusion

A recent President's Council on Bioethics Discussion Paper remarked 'In dramatic ways, the question of who, if anyone, owns a part of the body that is brought out of the darkness of the body's interior and into the light of the laboratory or clinic has become a meaningful one'.35 This is no longer an issue that can be skirted around. It has significance in many contexts, including directed donation. As Truog remarks 'Many of the concerns raised … regarding the directed donation of organs hinge on the question whether transplantable organs should be considered personal property or a societal resource'.36

Public policy may, and indeed sometimes must, properly place constraints on the 'distribution' of donor organs in the interests of society and the enterprise of transplantation as a whole, even where it is thought that permitting such practices would result in an increase in donated organs. This might even extend to restricting all 'gifts' by deceased persons to patients on the transplant waiting list as a class. However, insofar as the organs themselves are (within the current legal framework) appropriately seen to be initially subject to the 'direction' of the person from whose body such organs are removed, there should be compelling reasons to restrict such choices. Was Rachel Leake wrong in thinking that her daughter would have preferred to donate one of 'her' kidneys to her mum rather than a stranger?37

The burden of proof appears to rest with the State to justify limiting such choices. It is unclear why one should not 'prefer' one's close friends and relatives after death, even if no others. This ought not to tarnish the image of transplantation as a transparently fair system. Indeed, one must be aware that all donated organs are 'conditional' gifts, in terms of which organs and tissues one is intending to donate and the purposes for which such organs may be used.

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