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Priority to registered donors on the waiting list for postmortal organs? A critical look at the objections

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ABSTRACT

It has often been proposed to restrict access to postmortal organs to registered donors, or at least to give them priority on the waiting list. Such proposals are motivated by considerations of fairness: everyone benefits from the existence of a pool of available organs and of an organised system of distributing them and it is unfair that people who are prepared to contribute to this public good are duped by people who are not. This paper spells out this rationale and goes on to discuss the main principled objections that have been brought forward to such proposals. The most fundamental objection is that healthcare resources should be allocated in accordance with need, not with merit. The reply to this objection is that the principle of allocation according to need only holds in cases in which the provision of such resources and the fair distribution of the burdens of contribution are independently secured, as they are in an obligatory insurance system.

It has often been proposed to restrict access to postmortal organs to those people in need of an organ who have themselves consented to donation, for example by registering consent in a national registry or by carrying a donor card. A weaker form of this proposal would only give some kind of priority on the waiting list to registered donors, for example by giving them some bonus points in the allocation system.^{1–19} ⁱ On an alternative reading of either proposal it will be up to the donor to decide on either form of limitation of the possible access to his organs after his death (the so-called ‘club model’).

Many problems have been suggested for the implementation of such proposals, all or most of which may be solvable by intelligent design.ⁱⁱ More principled objections have also been put forward, some of them by now almost canonical. My aim in

ⁱ The system has been in force in Singapore since 1987, in combination with an opt-out system (for non-Muslims) and an opt-in system (for Muslims). Apparently, however, only a limited number of the population, especially of the Muslim population, are aware of this,¹⁷ note 97. Recently the Israeli parliament has incorporated the system into its new bill for organ transplantation, extending the beneficiaries from the signatory on the donor card to his first-degree relatives but, oddly, excluding living directed donors, cf footnote ix.²⁰ In the USA priority to receive a cadaveric transplant is given to living organ donors should they ever be in need of one,²¹ (p 779), referring to UNOS policy 3.5.11.6.

ⁱⁱ One of the frequently cited practical objections is that people who are unable to be donors, such as children and those infected with HIV, would be excluded from receiving organs or bonus points, but an express stipulation could be made for these groups that they would be eligible.¹⁶ ²⁰ The same also applies to patients in mortal danger.⁸ For a number of other problems attaching to implementation and proposed solutions to these problems, see Kolber¹⁵ (pp 314–19), cf. also Veatch.²²

this paper is, first to spell out the rationale for the proposal, and second to assess the force of the principled objections.

A DUTY OF FAIRNESS

The proposal is clearly inspired by considerations of fairness. Occasionally it has been defended merely by reference to the incentive it would provide for people to register as donors, but if one wants to provide incentives, monetary ones would be far more reliable. Following a classic exposition by John Rawls,²³ an extensive literature has been developed on the principle of fairness as a possible basis of political obligations.ⁱⁱⁱ Drawing on this literature we can spell out the conditions for the existence of moral requirements of fairness. They emerge in the context of a scheme of cooperation for mutual advantage, in which a good is being produced by the contributions of a number of people. Fairness requires that people who benefit from the scheme also take on a fair share of the burdens of contributing.

In the case of the procurement of postmortal organs for transplantation the relevant good is the existence of a pool of such organs and of a legally recognised and state-supported organisation for the distribution of them over the inhabitants of a certain territory (the UK for UK Transplant, six other European states for Eurotransplant, etc). The relevant contribution would be to allow oneself to be registered as a donor in a way that, according to the law (which may have to be changed to that effect), cannot be overruled by other people, in particular by one’s relatives after one’s death.^{iv} This will normally mean that one has taken active steps to have oneself registered, even in systems with a formal opt-out system.

Every inhabitant of the relevant territory is in a position to benefit from the availability of the pool of organs, not only the people who at a certain stage of their life have organ failure. For every person has a chance of becoming such a patient. In that case he will benefit from having a claim on the pool and, if he has such a claim, this also means that at the present time he already benefits from the assuredness provided by his power to press it if necessary.

ⁱⁱⁱ I have discussed this literature in Den Hartogh,²⁴ (pp 80–90), cf. more recently Klosko.²⁵

^{iv} Even in countries like The Netherlands in which an explicit consent legally cannot be vetoed by relatives, resistance by the family will in the end always be respected. It would therefore be possible in theory to conspire to register, claim one’s bonus points, and have one’s relatives use their veto power, but the benefit of bonus points seems too small to go to such lengths.

Requirements of fairness are not simply moral appeals; if the good to be cooperatively produced is sufficiently important, people have a right to claim not to be the victims of other people's free-riding or parasitic behaviour. How can this right be enforced? In some cases the relevant cooperative scheme that invokes the duty may concern the production of real public goods. In such cases it is not feasible to restrict the enjoyment of the benefits to people who have made a contribution. When a dyke is built, for example, everyone in the area protected by the dyke keeps their feet dry, regardless of whether they helped to pay for the construction of the dyke or not. We do not need to assume that in such cases—with the structure of an *n*-person prisoner's dilemma—no one will voluntarily contribute, but it is plausible that some people will not make a fair contribution, causing others who do not like to be their neighbours' fools, not to do so either. The result may not only be an unfair distribution of the production costs, but also harmful underproduction of the good.^v The requirement of fairness in such cases is categorical: to make a fair contribution. Therefore, the only way to prevent free-riding or parasitic behaviour is by conscription.

Most of the amenities produced under the auspices of the state, however, are not public goods in this strict sense (if these exist at all). Education, medical care, legal aid and even legal proceedings are not public goods; they could quite easily be produced on entrepreneurial initiative and be distributed through the market, in particular if the market in those goods is supplemented by a market in insurance provisions for those goods. The same is true for the provision of organs for transplantation. I will assume that we have convincing moral reasons for organising the production and distribution of these goods as if they were public goods.^{vi} In that case the requirement of fairness takes a binary form: either to contribute or to abstain from accepting the benefits, and we have an alternative way of preventing parasitic behaviour: limiting access.

It is often claimed that within a scheme of production of a public good no person can be required (at least not by considerations of fairness) to make a contribution to the scheme if the burdens of the contribution are not outweighed by the benefits to be expected from the scheme. That is supposed to be a minimum (not a sufficient) condition for calling the required contribution a fair one. Whether or not this is true, if the good produced is technically an excludable one, no such requirement needs to be made; we can leave it to each person to do his own weighing and choose from the two options he has (contributing or abstaining from the benefit) accordingly.

It is therefore not a possible objection to a prioritising scheme that, even if every inhabitant stands to benefit from the availability of organs, it is not true that for everyone the benefits outweigh the burdens. If that happens to be the case for you, you are indeed allowed to abstain from contributing, but in fairness you should not then claim any of the benefits either. As a matter of fact we know that the large majority of the inhabitants of each country expect that they will gladly make use of the availability of a postmortal organ if they need one, and that the large majority of the remainder who do at present not share that expectation will change their view at the moment of truth.^{vii}

^v It is possible to have the first but not the second result, for example in the case of blood supply, discussed below.

^{vi} In any case opponents of a prioritising system are not likely to object that the system should be replaced by a market in organs.

^{vii} In Germany, the USA and The Netherlands, respectively, 76%, 79% and 85% of a representative polled group say that they will accept an organ transplant if necessary, cf. Breyer²⁶ (p 163).

In many cases it is open to debate whether contributions should be proportional to benefits or to the ability to contribute. In the case of organ donation this discussion can also be bypassed. For each organ, there is only one decision each person has to make: whether or not to register his willingness to donate it. Because we cannot adjust benefits to contributions, or vice versa, it is also irrelevant that the benefits people may expect from the availability of a pool of organs are not equal, because they have differential risks of organ failure, due to their genetic constitution and lifestyle choices. You are perfectly free to believe that, because you do not consume alcohol or nicotine in large dosages, your personal risk of getting liver or lung failure is too low to make it worthwhile for you to 'pay' for your claim to an organ by being prepared to donate, but you should not then complain about losing that claim.

THE MAIN OBJECTION TO THE PROPOSAL

The main objection to this proposal is that it is diametrically opposed to a legally enshrined fundamental principle of health care; such care should be given exclusively in accordance with need, not with merit.^{27–29} The same principle also motivates the standard rejection of proposals to take into account, when providing care, the degree to which patients are personally responsible for the state of their health. Even if such patients are relying on a scarce commodity and could have avoided their health problem, this should not be taken into consideration when evaluating their claims to care. The patients' state of health and the prospects of improving it by medical intervention should be the sole considerations.

How should we assess this objection? First of all, it should be noted that one form of scarcity is not the same as another. The help required to repair the consequences of an unhealthy lifestyle would not necessarily be given at the expense of other help; it is a question of weighing it up against other spending options, but the number of post-mortem organs available at a certain point in time is a hard fact. There is admittedly room for manoeuvre in the supply of living donor organs that seems at least partly to depend on the length of the waiting list for post-mortem organs. This means that those who refuse to donate organs not only shift the burden on to other post-mortem donors but also on to living donors, for whom the burden is considerably heavier.³⁰ This makes it all the more problematical if they subsequently want to be eligible for an organ themselves.^{viii}

People such as these—and this is the most important point—do not only contribute to the scarcity by their claims to care, as patients with an unhealthy lifestyle do, but first and foremost by refusing to contribute to the supply of available organs.^{ix} Even if we have moral reasons to apply the criterion of need in abstraction from people's responsibility for a higher demand, it is something different also to abstract from their responsibility for a lower supply.^x The combination of voluntary

^{viii} Even if it is true that some living donors would prefer to donate an organ to their loved one, even if there was no scarcity of postmortal organs, the evident correlation between high levels of living donation and low levels of postmortal donation shows that refusing to be a postmortem donor actually shifts part of the burden of organ failure to living donors. Their claim to priority on the waiting list is particularly impressive, if their own problem of organ failure is likely to be causally related to their decision to donate.

^{ix} This distinction is often overlooked. If only for this reason, the fear that a priority system would erode the moral basis of the provision of healthcare³¹ (p 203–4) is misguided.

^x Remarkably, popular opinion is more in favour of taking lifestyle than taking contribution into account, cf. Breyer²⁶ (p 166).

contributions and allocation in accordance with need may characterise the ideal society but, as Karl Marx recognised, it is only a viable combination if people are motivated to produce sufficiently by the intrinsic rewards of labour. If they are not, it is a recipe for disaster to disconnect contributions and claims to receipt. For that reason nobody proposes to base claims to health care on the need for such care and at the same time to finance the costs of care from voluntary contributions. We can only afford to provide care whenever it is needed, even regardless of how this need arose, if and because there is a compulsory insurance system to cover the costs of such care. For the resources we need to pay for it do not grow on trees.

Therefore, those who appeal to the principle of need as the generally appropriate principle for the allocation of health care, must be consistent and plead for introducing compulsory donation of organs.^{25 32 xi} If, on the other hand, one wants to protect the 'perfect freedom' to refuse donation, it can only be the freedom 'to do the action and stand the consequences'. Those who adhere to distribution according to need, even if this results in the inability to meet needs, are guilty of a kind of fetishism comparable to that practised by advocates of purely altruistic donation who love charity better than their fellow human beings.^{33 34}

Compulsory health insurance does not cover all health care in any country. The remainder is not distributed according to need, but is exclusively available to people who contribute to the costs of this additional care, normally through supplementary insurance. The only agency that collects resources by calling for voluntary contributions and distributes them according to need is the blood bank, but this institution can only afford to do so because the supply of blood to date has been sufficient to meet the demand.^{xii} It would be unacceptable if voluntary blood donors could not themselves get the blood they needed for transfusion, if they would not be asked to tolerate parasitism, not only free-riding.

If a person who has not fulfilled his insurance obligations requires health care, he is not entitled to such care, but this does not mean that we just abandon him to his fate even if he were to die. In this case we would not have to exchange the principle of need in its entirety for the logic of insurance. Similarly, we would not have to exclude fully people who are not registered as donors from transplantation; it is possible merely to withhold bonus points from them, which we do allocate to registered donors.^{xiii} There is a second reason for limiting ourselves to this course of action: we are talking about a social benefit, a cooperative enterprise for mutual benefit and for alleviating distress, to which everyone is expected to make a fair contribution. This is quite a different matter from buying oneself into a cooperation that administers scarce organs.^{xiv} Priority on the waiting list

^{xi} Article 3 of the Additional Protocol to the European Convention on Human Rights and Biomedicine only permits medical criteria to be applied when allocating organs. (The Protocol has not yet been ratified by all member states of the European Union.) However, the Protocol also allows Eurotransplant or Scandiatransplant to use origin from a certain country as a criterion in order to prevent participating countries from becoming net organ exporters. This practice actually amounts to individuals being awarded bonus points for their compatriots' willingness to donate. Therefore, the objection to a prioritising scheme cannot be a principled one.

^{xii} Even so, as Inez de Beaufort reminded me, many voluntary blood donors understandably somewhat resent the fact that so many others benefit from their contribution without contributing themselves.

^{xiii} If we do not restrict the claim to organs to registered donors, the requirements of fairness are not fully satisfied, which may provide one additional reason to prefer opt-out to opt-in systems.^{10 35 36}

^{xiv} Incidentally, one should not expect too much from an appeal to people's self-interest. For most 18-year-olds, the possibility of organ failure is so remote that they will hardly attach any weight to insuring themselves against it at present.

should not be primarily regarded as a non-monetary incentive to recruit donor registrations.^{xv} The main point is to make it emphatically clear to all citizens that they are being asked to contribute to a social benefit that will also be to their own advantage.^{xvi} Withholding bonus points from non-donors is sufficient to make that point.

OTHER PRINCIPLED OBJECTIONS

A second common objection to the proposal to give registered donors priority on the waiting list is that refusals to donate may genuinely be prompted by motives that weigh heavily for the individuals involved. These should not be lumped together with pure indifference and conscious parasitism and, as such, they do not deserve to be penalised.^{38–40} The example that is often cited is that of religious objections against donation.

This is a revealing example. For people who sincerely believe that the premature loss of an organ would be deleterious to their next stage of reincarnation or the resurrection of their bodies at the last trumpet should be the last ones to want to profit from others losing their organs, and should therefore not consider themselves entitled to receive them. Such people should not regard the loss of this entitlement as a penalty either, but rather as the clear implication of their own view. Even people who are deterred from donation by vague fears must realise that these indefinable dangers also threaten the individuals from whom they might wish to receive donor organs. Those who refer to 'penalties' and 'rewards' with regard to the allocation of bonus points are already presupposing that the 'normal' distribution is according to need, so that each deviation from this requires special justification.^{xvii} In a cooperative enterprise, however, 'normal' distribution is determined by adjusting claims to contributions, or vice versa. If refusers do not lose more than a part of their claims, they are therefore being reprieved rather than penalised.

A third objection is that the bonus point plan is based on too limited a notion of relevant contributions. A criminal sentenced to life imprisonment who is a registered donor is awarded bonus points, whereas an individual who has served society in all kinds of ways, but who refuses to register as a donor in order to spare his family's feelings, is not awarded any such points.^{41–43}

This objection largely derives its rhetorical power from the foregoing: it considers bonus points as a small part of a large scheme to reward moral merit in general. That is not the idea.^{xviii} If we leave out any connotations of rewards and penalties, we see that organ transplantation cannot be anything other than an independent social benefit that cannot be mingled with other collective efforts on behalf of the public good. The reason is that this benefit depends on contributions in the shape of organs that cannot be exchanged for other contributions by using money as a measure of amalgamated value. As

^{xv} This may be the reason why, out of all systems that introduce incentives for donation, priority on the waiting list encounters the least objections from the public; 41% of Americans,³⁷ 44% of Germans²⁶ (p 166) and the Dutch find such systems acceptable (<http://www.eenvandaag.nl/docs/opiniepanel/nierdonatie/uitslagorgaandonatie.pdf>).

^{xvi} For this reason it can be argued that priority on the waiting list is compatible with a legal provision such as Article 2 of the Dutch Organ Donation Act: 'Consent to the removal of an organ, granted with the object of receiving compensation for this removal... shall be void.'

^{xvii} For the same reason, it is also incorrect to say that a regulation demanding additional contributions from people whose need for care is due to their own lifestyle 'penalises' such people. They are only prevented from shifting the consequences of their personal choices on to others.

^{xviii} For a general criticism of this idea see Gutmann and Fateh-Moghadam²⁷ (p 86).

a comparison, imagine that a remote village is threatened by imminent flooding, which makes dyke surveillance imperative. Everyone in the village over a certain age has to participate in order to make this surveillance effective. If one person refuses to cooperate and the dyke subsequently bursts at the very point where this person should have been standing, he can hardly excuse himself by saying that he is already paying more taxes than others.

I conclude that the principled objections to the proposal to give priority to registered donors fail. Whether the proposal can actually be implemented in a fair and cost-efficient way remains to be seen.

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