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# Advance commitment: an alternative approach to the family veto problem in organ procurement

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## ABSTRACT

This article tackles the current deficit in the supply of cadaveric organs by addressing the family veto in organ donation. The authors believe that the family veto matters—ethically as well as practically—and that policies that completely disregard the views of the family in this decision are likely to be counterproductive. Instead, this paper proposes to engage directly with the most important reasons why families often object to the removal of the organs of a loved one who has signed up to the donor registry—notably a failure to understand fully and deliberate on the information and a reluctance to deal with this sort of decision at an emotionally distressing time. To accommodate these concerns it is proposed to separate radically the process of information, deliberation and agreement about the harvesting of a potential donor's organs from the event of death and bereavement through a scheme of advance commitment. This paper briefly sets out the proposal and discusses in some detail its design as well as what is believed to be the main advantages compared with the leading alternatives.

“We have the doctors ready, willing and able to undertake surgery, we have people dying with usable organs and we apparently have a compliant public. Why then is the programme so strapped?”<sup>1</sup>

It is a well-known fact that the demand for transplant surgery significantly outstrips the supply of available organs. In the UK alone, 506 patients died in 2007–8 awaiting a transplant, while many more patients continue to experience significant loss of quality of life for the lack of a much-needed organ transplant.<sup>2</sup> In an attempt to increase the number of available organs, many countries have begun to rethink their approach to cadaveric donation. Controversial proposals include the use of financial incentives or advancing the case for compulsory organ donation.<sup>3–7</sup> More practically, a number of countries (eg, Belgium and Sweden) have recently switched their organ procurement policy from a system of opt-in (informed) consent to a system of opt-out (presumed) consent, which sanctions posthumous organ removal unless the donor has explicitly objected. The precise benefits of presumed consent remain in doubt, however; there would probably still be a significant shortage of organs even if we accept optimistic estimates that a move towards presumed consent laws would lead to an increase of approximately 25–30% in donation rates.<sup>8</sup>

With family members reportedly blocking approximately half of the available donations, we believe the key to increasing the availability of

cadaveric organs lies in effectively addressing the ‘family veto’.<sup>9–11</sup> In contrast with proposals that aim to restrict the impact of family members on donation, we outline a scheme that gives families a positive role in the decision-making process, provided the donor values their involvement. Under our scheme, donors would appoint a designated second consentor (DSC), in most cases likely to be a family member, who would as part of the organ donor registration process signal their advance commitment to uphold the donor's decision after the death of the latter. Our proposal gives moral weight to the distress caused to family members (and medical staff) in seeking permission for organ harvesting at a time of bereavement, while at the same time respecting the autonomy of donors and the needs of patients awaiting a transplant. We should make it clear from the outset that, under our proposal, the right of the family to veto organ donation would not be infeasible. It does, however, offer donors and families the opportunity of a ‘deliberative space’ in which the decision to donate can be taken at a moment which is likely to be less distressing and more conducive to the making of a genuinely informed decision.<sup>12 13</sup> Our proposal has a number of pragmatic advantages that should appeal to those who disagree on ethical grounds with an approach that affords validity to the claims of family members. In particular, disregarding the views of donors' families, even if morally defensible, would be politically unpalatable and could lead to a significant decrease in organ donors. Our proposal, by contrast, is politically feasible and effective in increasing the number of available organs for transplant.

## FAMILY VETO MATTERS

The existence of a widespread family veto may seem puzzling given that families typically have no real legal right to a say, once the deceased has validly expressed her intention to donate. In the UK, for example, the Human Tissue Authority Code of Practice on Consent advises clinicians to encourage family members and others close to the deceased to accept the wishes of the deceased, emphasising that they have no legal right to veto or overrule those wishes.<sup>14</sup> Any reluctance to proceed with cadaveric organ removal against the wishes of the family may be due less to fear of legal liability than to an understandable reluctance on the part of medical practitioners to add to the distress of grieving family members. Medical staff routinely acknowledge the added distress or loss of control of family members confronted with requests to remove body parts from a recently deceased spouse, child or parent.<sup>15</sup>

The belief that requests to approve organ donation may cause distress to grieving families explains not only reluctance on the part of transplant staff to proceed with organ harvesting without explicit consent by next of kin, but similarly reluctance on behalf of medical staff even to approach families at this difficult time. Unfortunately, delay is problematical because the chances of a successful organ transplant decrease significantly as the period from the time of the donor's death increases. Whereas some commentators believe medical staff should be held under a required request obligation to enquire routinely about possible organ donation, it is also acknowledged that this puts staff under considerable emotional pressure.<sup>16 17</sup> Needless to say, the combined effects of reluctance by medical staff to request family consent and reluctance by next of kin to give consent has a deleterious effect on the supply of cadaveric organs.

One obvious solution would be to proceed with a policy of routine salvaging or the compulsory removal of donor organs independent of the family's objections.<sup>5-7</sup> In some cases this may involve a subtle policy of distinguishing between informing family members of harvesting but not actively requiring their consent.<sup>18 19</sup> Although there is some evidence that such a policy could improve organ supply, it remains unclear how one would deal with families that persist in their objection. The proposal of allowing next of kin to register their objection while nevertheless proceeding with harvesting smacks of cheap symbolism and will probably contribute to families' feelings of disrespect and loss of control. Ignoring the complex emotional dimension associated with cadaveric organ donation is also likely to backfire on the supply of organs. This was vividly illustrated when, in February 2007 in Singapore, the kidneys and corneas of Sim Tee Hua were harvested against the family's explicit objections. Because Sim had not signed a statement refusing to donate his organs, the hospital decided to go ahead with organ removal and ended up having to restrain the distressed family members by force while whisking away Sim's body for harvesting. The Sim case caused a massive public outcry and resulted in a significant drop in potential donors.<sup>20</sup>

If ignoring family distress—either by instituting required request policies or by ignoring the family perspective altogether—amounts to bad policy (as well as, perhaps, poor ethics), are there any alternatives that take the family veto seriously while also addressing the organ deficit? In the next section we outline one such alternative, based on a weak form of advance commitment.

### **ADVANCE COMMITMENT AS AN ORGAN PROCUREMENT POLICY**

Suppose you wish to donate your organs. You sign onto the organ donor register and make a declaration of intent that your organs may be posthumously removed and used for transplant purposes. In our proposal, however, you are also asked to nominate a DSC, who will be notified of your decision to become a donor and asked to register her agreement to allow your organs to be harvested upon death. While there is a superficial similarity between our proposed DSC and the nominated representatives envisaged under Section 4 of the UK's Human Tissue Act 2004, there are also crucial differences.<sup>14</sup> When the DSC agrees to undertake this responsibility she receives an explicit request to support the posthumous removal of the donor's organs, under the conditions stipulated by the donor (if any). Importantly, in view of ensuring donor autonomy, the DSC cannot add or alter any of the stipulations of the donor's consent.

After being fully informed and ideally having discussed key aspects of the decision with the donor, the DSC next registers

a statement of intent to agree to organ removal upon the event of the donor's death. The DSC may of course refuse to do so after having reflected on the request, in which case the donor would be entitled to designate another person to fulfil this role. Similarly, if the DSC first agrees but then later on formally rescinds her decision, again the donor is informed and may choose to reassign the DSC responsibility to another person.

Upon the death of the suitable donor, the local donor coordinator would normally inform the DSC. In most cases, we envisage that it would then be straightforward to proceed with organ removal, and less harrowing for both medical personnel and family members than under current arrangements. In the event that it is not possible to contact the DSC, the fact that advance commitment has been obtained would be a *prima facie* reason to proceed with organ removal. Another possibility is that the DSC raises an objection to organ removal after the death of the donor, perhaps under pressure from the immediate family in the hospital. Under our scheme the local donor coordinator would have to accept that decision and abort the process of organ removal. It is true that this would, in some sense, violate the wishes of the donor as well as ignoring the impact of this decision on the organ recipient. Our proposal in this sense offers only a weak form of commitment. Although it is possible to envisage a scheme in which the DSC's assent, once given, would be difficult or impossible to revoke, this may be self-defeating if it discourages second consenters and perhaps even donors from signing up in the first place. Alternatively, we might consider combining the scheme outlined here with the use of financial incentives for those signing up to the scheme. Elsewhere we propose that such incentives could take the form of an organ transplant tax credit.

The introduction of a DSC into the organ donation process raises a number of concerns, however. From the perspective of respecting donor autonomy an important question concerns the freedom of the donor to choose her DSC as she pleases. We envisage that in most cases, most donors would opt for a family member, and that the exercise of this choice would be relatively uncontentious. Nonetheless, leaving aside children and others who do not have the full capacity to give consent, it is important for the donor to retain the power to choose for a number of reasons. Most straightforwardly, a donor who rightly anticipates that, say, her mother would be distressed by the mere responsibility of having to agree on this matter—independent of whether she believes donation is the right or wrong course of action—surely has the right (perhaps even a weak obligation) to assign someone less burdened to this task. More controversially, in some cases the donor might not have a close relation with any of her relatives, and might want to assign a friend or even colleague who would in those circumstances be much better placed to exercise a trusteeship function than family members. In other cases, there might be a problem when the law does not recognise certain intimate relations as full partnerships—as is the case for gay couples in many countries—and this way the donor ensures the 'correct' partner's status in this decision.

Quite a different sort of reason in favour of the donor's right to assign their DSC is when she feels some of her close relatives would manifestly refuse to assent to the removal of organs for transplant. For a donor who is committed to have her organs used for transplant purposes to know that this will be vetoed by her family surely constitutes a level of antemortem distress that we would like to avoid if we could. In such cases it is conceivable, even likely, that some or all family members would find themselves in dispute with the expressed wishes of the donor and by extension with the commitment given by the DSC. The donor's choice of DSC may not be decisive in securing her wish to donate,

because the DSC may ultimately give way in the face of sustained family objections. Nonetheless, the presence in such cases of the DSC as a living advocate for the donor's wishes, would shift the balance towards the side of donor autonomy. Moreover, although there is no easy solution to such hard cases, the DSC would in most cases be best placed to balance the competing considerations of the donor's expressed wishes and the likely effects on the family.

Another issue in relation to the role of the DSC concerns whether donors should be restricted in nominating a single person as DSC or instead be allowed to nominate several individuals to undertake this important role? Presently, under the Human Tissue Act 2004, an individual may nominate more than one person to give consent on her behalf after death, jointly and severally.<sup>14</sup> A case could be made for a scheme based on a single nominated DSC, as that role is essentially merely to ratify the wishes already conveyed by the donor, lessening the imperative of obtaining permission again after the death of the donor. This would weaken the case for appointing several people in order to make sure at least one of them can be reached in time at the crucial moment of organ removal. Furthermore, family disputes may also be less likely to impede organ removal if a single individual is designated. On the other hand, donors are in a good position to know their own family dynamics, and presumably would in most cases not choose more than one DSC without good reason. Even if this more permissive approach were to create complications in exceptional cases, it might be a price worth paying for maintaining a 'minimally presumptuous' approach.

### THE ADVANTAGES OF ADVANCE COMMITMENT

We discern four reasons for thinking the weak advance commitment scheme outlined in the previous section would constitute good organ procurement policy: respect for autonomy; better informed consent; accommodation of emotional distress of both next of kin and medical staff; and a significant increase in the supply of cadaveric organs.

First, we believe our proposed scheme significantly improves the autonomy of the donor in terms of influencing what happens to her organs after death. The scheme robustly secures donors' negative right not to have their organs taken without their consent; on this dimension, it is fully at a par with current informed consent policies and significantly improves on presumed consent policies.<sup>10 11 17</sup> In addition, our proposal offers considerable advantages in terms of respecting donors' positive claims to determine what happens to their body after death.<sup>16 17 21 22</sup> By allowing donors substantially to determine who among the next of kin (or even outside the circle of family relations) will have the power to veto their preferences on organ donation posthumously, they thereby influence what happens to their body after death. One significant advantage of our advanced commitment scheme is that the DSC is not put into a position of having to give a substituted judgement as to what he or she thinks the donor might have wanted. One aim of our scheme is precisely to reduce as much as possible epistemic uncertainty about donor preferences.

Second, our scheme significantly improves the informed aspect of organ donor decision-making, both in terms of the donor and next of kin. Despite numerous campaigns to raise public awareness about organ donation, the level of disinformation remains quite staggering. In fact, one of the main worries with the two leading alternatives to current organ donation policy—presumed consent and mandated choice—is that they seem to allow many potential donors to 'consent' on the basis of information that scarcely qualifies as such.<sup>22–24</sup> At

present incentives to inform oneself are weak at best. By contrast, the combination of having both donor and a member of the family sign onto a national register may improve both the active seeking of information as well as genuine deliberation afterwards, presumably even discussion among various members of the family. All of this seems conducive to boosting informed consent not only by the donor, but particularly by the family, who under current arrangements are typically ill-informed when asked to reflect on organ removal requests immediately after the death of the donor.<sup>12 13</sup> Note that improved quality of informed consent also applies to those who refuse to agree to the harvesting of their loved one's organs. It is reasonable to assume that the proportion of people who make such a decision in our scheme will be better informed compared with alternative policies simply because opportunities to become informed and deliberate are disconnected from the distressing event of death.

Third, in line with one of the major reasons why we should take family vetoes seriously, we argue that our proposal will in the majority of cases significantly decrease the additional distress incurred by family members as well as medical staff at, and immediately after, the death of the donor. This is most obviously the case for family members to the extent that much of the required decisions have been taken well before death, relieving the next of kin of the added emotional pressure related to such decisions. Moreover, the reduction in epistemic uncertainty, discussed earlier in this section, would be expected to make the DSC's decision to abide by her earlier assent easier. It has been suggested that any argument in favour of taking the distress of the family seriously would imply removing the family veto altogether.<sup>11</sup> However, this argument fails to take into account distress associated with loss of control and (perceived) lack of respect by the family, and we maintain that an advanced commitment scheme that removes the decision process from the time of bereavement remains the better option. In our scheme, all that is required is that the DSC and other family are informed of organ removal; to many family members the fact that the person did register as a donor, and that the family is genuinely represented in the decision process through the DSC, may be sufficient reason not to engage further with the organ donation process. This is certainly the case when the whole immediate family was fully involved in the advance commitment process and a genuine joint agreement was reached.

One immediate objection to the last point is to suggest that advance commitment in fact increases distress when families disagree with the DSC. It is hard to deny that in some cases this may turn a serene period of bereavement into one of internal strife and struggle. However, we suggest that the proportion of families who experience this more acrimonious engagement with the donor process is likely to be much smaller than under the current system for two reasons. On the one hand, in many cases a good number of family members will have been involved in the decision process well in advance, improving the chances of reaching a collective decision. On the other hand, those who were not involved may have less trouble agreeing with 'one of their own' rather than having to deal with a representative of the transplant team. As mentioned before, it is often the loss of control and what is regularly perceived as the insensitivity of medical staff broaching the topic of organ donation that distresses the next of kin.<sup>12 13</sup> The advance commitment scheme would address this aspect of the problem outright. As for the remaining cases in which families quarrel among themselves, or when the donor chooses someone outside the family group to act as a DSC, it cannot be an objection to our scheme that we cannot fully resolve internal

division in all families because any scheme that involves individuals having to agree collectively on a delicate issue will encounter the same problem. Under our scheme at least the donor has granted one or more persons the authority to impose a decision on the family if conflict cannot be resolved. Even when family disputes cannot be resolved, it is still surely desirable to have some form of binding settlement, in order to limit the duration of family conflict.

Next, we must consider the important point of relieving medical staff from some of the distress associated with having to juggle the moral commitment to saving lives through organ donation with the acknowledgement of family members' emotional distress.<sup>15</sup> In this respect our proposal has two major advantages. The fact that a DSC has already agreed considerably shortens the amount of time and effort required to convince next of kin to consent, including being torn between either failing the family or failing the potential recipient in need of a transplant organ. Furthermore, the fact that legitimate consent pre-exists allows for a low-distress approach to organ removal even when some family members object, as medical staff can proceed knowing the family perspective has not been entirely disregarded. Compared with alternative proposals advance commitment can make a plausible claim to decrease distress on all parties.

Finally, we believe our proposed scheme has the potential to boost the current supply of cadaveric organs significantly. This is in large part because of the three advantages discussed above. If current estimates that family vetoes effectively block approximately half of potential donor organs are correct, we should expect to increase this supply significantly when the autonomy of donors is respected. Similarly, more information should positively affect the supply of organs if much current objection to organ donation is based on donors and family being ill-informed. A further interesting side-effect is that family members who are asked to become a DSC are likely to reflect on their own reasons for (not) becoming a donor. Finally, respect for family distress will affect the supply in at least three ways: by making it easier for encouraging family members to agree to organ removal; by encouraging greater numbers of donors to sign up with the reassurance that their families will not experience an unnecessarily distressing process of request consent; and by transplant staff more routinely proceeding with organ removal. One important reason tied in with this last point is that in cases in which the next of kin cannot be reached in time, despite a good faith effort to reach them, transplant staff can go ahead with organ removal in the knowledge that family consent has already been obtained. This would imply a sizeable reduction in the number of organs currently going to waste because the family cannot be reached in time.

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