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PHILOSOPHICAL CONSIDERATIONS

Donation decisions after death: The case for a family veto



Décisions de dons après la mort : un cas de veto familial

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Received 3 August 2017; accepted 23 September 2017
Available online 21 November 2017

KEYWORDS

Embodiment;
Family override;
Family veto;
Informed consent;
Organ donation;
Relational autonomy;
Transplantation

Summary This paper argues that families should be able to refuse to donate the organs of their deceased relative, even when their relative was registered as an organ donor. Families generally hold important relational claims on the body of a decedent, claims which should be respected in the form of allowing families to “veto” postmortem organ donation. Current arguments for and against a “family veto” will first be addressed in order to demonstrate their insufficiency. Typical claims against a family veto either are overly utilitarian, or they appeal to the donor’s autonomy and face the problem of explaining why informed consent should be respected after death. I offer a new approach for this issue, which considers relational autonomy and embodied relationships. Thus, I conclude that organ donation decisions should be balanced between the potential donor and their family in a double-veto system.

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MOTS CLÉS

Incarnation ;
Outrepasser le veto
familial ;
Veto familial ;
Consentement

Résumé Ce texte montre que des familles peuvent refuser le don d’organe de leurs défunts, même si ce dernier avait fait part de sa volonté expresse. Les familles, en général, réclament le corps de leur décédé et ce droit de réclamation devrait permettre aux familles de s’opposer à une donation d’organes postmortem. Les arguments pour ou contre ce veto des familles seront exposés dans un premier temps pour montrer leurs insuffisances. Les oppositions à un veto familial sont utilitaristes, font appel à l’autonomie du donneur et mettent en avant que le consentement éclairé doit être respecté après la mort. J’offre une nouvelle approche

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éclairé ;
 Donation d'organe ;
 Autonomie
 relationnelle ;
 Transplantation

qui considère l'autonomie relationnelle et l'incarnation. Je conclus que les décisions de dons d'organes doivent être mises en balance entre le donneur potentiel et le veto familial par un système de double-veto.

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A tension exists between organ donation policy and practice. As it currently stands, laws in most countries do not recognize familial decisions regarding organ donation when the deceased has already consented to donation. Still, the practice of asking families for permission, or respecting their adamant refusals, has persisted in many countries where there is no legal precedent for such practice [1]. Critics from the United States, the United Kingdom, Canada, and Australia, among others, have railed against the "family override", calling it a violation of autonomy that does nothing to help long transplantation waiting lists [2]. In order to overcome this policy–practice disparity, many have suggested better means of informing health care professionals and families of the legal requirements for consent [3]. In other words, make hospitals, organ procurement organizations and families acutely aware of the family's lack of legal authority. Change practice to match policy.

Rather than trying to overcome this disparity with legal precision and family pamphlets, let us first consider why the practice of asking for familial permission is ongoing. Perhaps, this practice has persisted because our moral sensibilities indicate that the family does have some kind of claim on the body of the deceased. The remainder of this paper will make the case that such claims legitimate a family veto – allowance for the family to refuse donation their relative's body even when the relative had authorized donation. I'll argue this through showing the ineffectiveness of the current frameworks operative in the literature on organ donation – utilitarianism and respect for individual autonomy – in favour of an approach rooted in relational autonomy and the embodied ontology of relationship. In effect, a 'double-veto' system would best respect both the potential donor and the family as stakeholders.

Objections to a family veto

Burdens, regrets and poor information

Several concerns regarding family vetoes have been in circulation. In some cases, the option to veto seems to place an unnecessary burden on families who are already distressed [1]. Furthermore, a family in grief might not be in a position to make a well-thought donation decision. Their stress and grief might impulsively lead them to refuse donation, though this may not reflect their settled values (or the settled values of the deceased) [4]. In addition to the stress of the situation, the family is often ill-informed about the process of donation [5]. Lastly, there is evidence that some families can come to regret overruling donation and often such regret leads to a willingness to donate in the future [6].

These arguments bring up real issues in decision-making about organ donation, but they operate on the assumption that the family has no significant claim on the decedent's body. The thought is that asking for familial permission is merely a nicety or formality – the family's choice has no real moral bearing on the issue. If that is the case, why not drop the niceties and save the family some grief? If, however, families have any legitimate claim to the corpse of their loved one, they should not be stripped of a donation decision simply because they may be stressed or grieving. If they are ill-informed, there should be better efforts to inform them rather than disallowing their decision. Consider if these same arguments were applied to the donor's choice: "it would place undue stress on a potential donor to ask them to contemplate their own death, so we should not allow them any choice in the matter". This line of thinking is ridiculous, yet is being used to disallow family input.

If families really have a claim on the body, then donation should not be ruled out on the basis of undue stress or grief. It is certainly morally important to allow space for grief, but it is also important to communicate with the family carefully and inform them thoroughly regarding donation. There are certainly complications in the decision-making process for organ donation, but such complications do not entail that the family should not be able to decide.

Need for organs

Another argument takes a particularly utilitarian turn, citing the discrepancy between the supply and demand of organs. It can be stated this way: because a family veto lessens the supply of organs available for transplantation and since it is good to supply organs for transplantation and thus save lives, therefore there should not be a family veto. Some even go so far as to say a family veto can "contribute to avoidable harm" [1]. There is research to back up such claims – the British National Health Service estimates that family refusals accounted for 1200 missed transplant opportunities between 2010 and 2015 [3].

If this logic is to be taken seriously, then it is not clear why we should allow anyone to veto the donation of his or her own organs. The same logic could argue: because any donation refusal lessens the supply of organs available for transplantation and it is good to supply organs for transplantation and thus save lives, there should not be an option for donation refusal. This kind of reasoning often leads to the strange sorts of utilitarian thought experiments akin to the film *7 Pounds*, where Will Smith's character kills himself in order to donate his organs to others.

There can be good utilitarian reasons to support a potential donor's donation refusal, as there can be good utilitarian reasons to support a family's donation refusal. Still, if

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