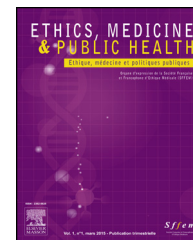




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PHILOSOPHICAL CONSIDERATIONS

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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<http://dx.doi.org/10.1016/j.jemep.2017.09.010>
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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

working within a strictly utilitarian framework, those arguments are often if not always overshadowed by the pressing need and obvious benefit derived from donation. Such a framework violates the intuition that the individual has a right to refuse any procedure that disrupts their bodily integrity, even after death. It is a further question whether the family has any such claim over the corpse of their loved one.

Instead of falling into the abyss of utilitarian calculi, we respect consents and refusals for organ donation. We do not think societal needs warrant an unlimited claim on bodies, dead or living. So, the primary question about consent in organ donation should not be “what consent practices maximize organ donation?”, as has been the unfortunate trend in the literature, but instead “what consent practices justify organ donation?” We need to consider questions of valid consent and authorization for the manipulation of a deceased body, which the remaining argument attempts to do.

Respect for autonomy

By far, the most common argument against a family veto centres on respecting the autonomy of the deceased [7]. One formulation of this argument analogizes intent to donate with informed consent. Autonomy is lauded as a principle of biomedical ethics and translates into the practice of asking for informed consent from a patient before medical treatments or procedures. Family members can become surrogate decision-makers for patients if the patient is incapacitated, but a surrogate is meant to act in line with the intentions and values of the patient, rather than their own. Following this logic, if a person with decision-making capacity is informed about organ donation and its implications and agrees to donate their organs, then a surrogate is not necessary to interpret the intentions and values of the deceased. They autonomously consented to organ donation and since this is the only permission needed a surrogate or family veto is unnecessary. It should be noted, however, that this does not create an obligation on the part of the medical team to donate their organs – the deceased would not be considered wronged in any way if donation did not proceed.

Another stronger version of the argument from autonomy would consider the deceased wronged if their authorization to donate did not translate into actual anatomical donation when possible. Their ‘authorization’ would be conceived more so as a decision to donate. This is often considered analogous with regulations regarding property rights and wills of the deceased. Just as we respect a will, which determines the distribution of resources amongst the living, we should respect a decision to donate as a distribution of anatomical resources [8]. Of course, there are few cases where one’s death is amenable to transplantation, so this decision to donate should be thought of as a decision to donate insofar as medical circumstances allow it. However, if the family is the primary factor-preventing donation then they can be said to have wronged their deceased loved one by overriding their decision. If violating a will is wronging a deceased person, in some sense, then violating a decision to donate is a wrong in the same sense.

Due to the prevalent and complicated nature of arguments based in respect for autonomy, refutations of this

approach warrant their own discussion. Problems with this approach will be addressed after discussing common arguments for a family veto.

Common arguments for a family veto

Utilitarian

A number of arguments in favour of a family veto have been articulated, some more sophisticated than others. Shaw et al. outline six common arguments, many of which are based in a utilitarian framework. For instance, they argue that a family veto may minimize family distress, minimize staff stress and may help maintain trust in the organ donation system. While these arguments pick out ethically relevant factors, they are ultimately ineffective because they fail to address why these consequences outweigh others. One merely has to point out that saving lives is a better consequence than minimizing distress and these arguments lose their force.

Another argument points out that family cooperation is needed in many cases to aid in the donation process [1]. If a family’s option to veto ultimately makes them more cooperative in the donation process, then transplants are more likely to be successful. A family veto would ultimately save lives, or so the argument goes. The problem is it is not at all clear this would be the case. While a family veto might improve cooperation, it also raises the real possibility that the family will refuse to donate and thereby prevent organ transplantations that otherwise could have happened.

As stated above, a utilitarian approach is already wrong-headed for this kind of issue. Utilitarian arguments have difficulty arguing that any kind of authorization for donation is needed when compared to the overwhelming need for human organs.

The family knows what they wanted

Another common argument maintains that a family veto helps ensure that the decedent’s true donation decision is followed. Family members generally have insight into their deceased relative’s wishes and intentions – insight which might contradict their recorded donation decision. Perhaps there is reason to believe the potential donor was not well informed about donation, or perhaps they expressed a wish to be buried a specific way. One clinical ethicist in the United States described a case where a family opposed donation because “He had problems with drugs and alcohol and was rarely one to reflect on his choices, and in conversations about issues like donation, he never spoke of wanting to be a donor” [9]. Because the family’s opposition was based on insight into the patient’s wishes, and not on their own wishes, the hospital did not press for organ procurement.

Ana Iltis is one proponent of this view. She argues that a checkbox at the Department of Motor Vehicles, the primary means of consenting to organ donation in the United States, does not necessarily express a deep wish or desire to donate. Therefore, a family’s input is useful in determining the true interests of the deceased. In addition, she advocates for a more robust informed consent process rather than the current process of “mere authorization” [10].

By this logic, the family's wishes should still be overridden if it can decisively be shown that a potential donor desired to donate. This view subordinates the family's role to another information source on the potential donor's autonomous decisions and ultimately favours the decisions of the deceased over the decisions of their living family.

Relational autonomy

Shaw et al. list 'relational autonomy' as their last argument for a family veto, though this argument has not actually been developed in the literature on organ donation. This kind of notion goes against the individualized autonomy popular in Western philosophical ethics, considering that autonomy should be construed relationally as recognition of our social nature. This means that the decision to donate organs is not a decision for the individual to make alone, but should also have input from family and close friends. In contrast to the last argument, an argument from relational autonomy considers both the donor's wishes and the family's wishes to have decisive value. Still, it is not clear that this means the family's wishes should override the wishes of the potential donor, as would be the case with a family veto. This argument, with its possible objections and nuances, will be developed.

In favor of the family veto

Problems with arguments from autonomy

There is general agreement that some authorization or consent is needed to perform organ donation – but who consents? Arguments against a family veto prioritize the decision-making of the deceased person, but it is not clear why this should be the case. In her article "Organ donation after death – should I decide, or should my family?", Paula Boddington argues that the medical notion of informed consent does not easily apply to organ donation. Typically, consent from a patient is important because their bodily integrity is at stake and "medical decisions are lifestyle decisions" [11]. In short, informed consent is important because the patient is the person most directly affected by a medical procedure. While organ donation is a lifestyle decision in the sense that it can reflect one's values and even alter end of life care, a person is no longer affected by such decisions once they cease to live. After death, the justifications for informed consent fail to hold sway. While organ donation takes place in a hospital, it is not a standard medical treatment subject to informed consent. T. M. Wilkinson echoes this sentiment, arguing that "the fact that people are dead must make some difference to the strength and nature of their claims when compared with incompetent living patients, so the analogy is, at least, imperfect" [12].

The second argument for respecting the autonomy of the decedent draws an analogy with property rights and wills. The medical concept of informed consent fails to justify enforcement of a donor's wishes, but perhaps other legal norms related to death apply to organ donation. We respect wills – legal documents outlining choices for the allocation of property after the owner's death. Why not consider organ donation another choice having the same status as a will?

While such a comparison sounds promising, it proves problematic upon closer examination. Organ donation decisions and wills are analogous only if the body is framed as another resource or piece of property to be allocated. This framing is closely tied to a Lockean understanding of the body, which views the labour of the body as the foundation of property rights [13]. Though Locke did not intend it, the body itself can be easily thought of as the "ultimate property" of the person, the thing that the person necessarily owns and can use to build the rest of their property.

The concept of the body as property has generally been rejected in the western legal tradition. We do not allow the buying and selling of human body parts, nor do we consider dead bodies to be property. As Norman Cantor notes, both the American and British judiciaries "ruled that a corpse was not, from a legal perspective, property either of the deceased or of his or her descendants" [14]. Still, there is a trend in giving the corpse a legally protected "special status" on the basis of being "the tangible representation of a unique persona bearing special attachments to survivors". With this came protections against mistreatment and efforts to protect premortem determinations regarding the disposal of remains. Notice, though, that these protections were not afforded because the corpse is thought of as property, but because the corpse is thought of as a representation of the person to survivors.

Because embodied persons are different from objects or other things that can be owned, families experience the body of their loved one different from the car or house of their loved one. The body is not merely an impersonal object, but a material thing that was recently imbued with life and personhood. Cherished objects did not at one point talk to others, embrace others, feed others or birth others. The meanings associated with the person are written more deeply into the body than into any other thing they owned.

One might respond that even if we do not see a corpse as property, there are still good reasons to consider the decedent's prior decision for disposal of remains binding just as other premortem decisions (such as those in a will) are binding. This raises a question: why do we respect wills? The person is no longer present, so why might a will be something worth respecting? I suspect it might be this: the resources allocated in a will are meant to enrich the family's or community's life in ways the decedent felt appropriate, based on their values, knowledge of their resources and of the needs of those around them. We trust that they would have had a good sense of these things. Furthermore, a greedy free-for-all may ensue if we let others override their decisions. In short, we respect wills not because property rights exist beyond death, but because respecting the will of the dead seems good for the living. While it is straightforward to know how money, or a house, or a car might benefit others, it is not always so clear to a person how their body will be needed beyond death. The process of grief cannot be so easily predicted.

Boddington is right in stating, "it is not a straightforward matter to apply models of autonomy based on the interests of the individual over his or her living body, to the case of the dead body" [11]. Models of informed consent, property rights and wills are not sufficient to account for the particular kind of issues involved in postmortem organ donation. While there are certainly good reasons to consider and

respect the wishes of the dead, it is not clear that this should trump the wishes and needs of the living.

Why do appeals to autonomy in organ donation remain so strong even though the foundation for such appeals remains so weak? I suspect, along with others, that the potential good of organ donation often overthrows a closer consideration of such arguments. If the decedent's decision to donate can be refused by the family, then fewer organs will be available for transplantation and fewer lives will be saved. Thus, there is strong incentive to support the decision of the decedent over and against the family. Some, such as Jeff Bishop in his book *The anticipatory corpse*, go so far as to consider both the development of brain death criteria and the emphasis on respecting the donor's autonomy as political moves rather than legitimate biological or ideological considerations [15]. While I will not attempt to comment on brain death criteria here, it is very possible that the rhetoric around respecting the donor's autonomy is mobilized to promote organ donation, rather than to protect the donor's interests.

A new approach

Rather than approaching organ donation through the frameworks of utilitarianism or traditional conceptions of respect for autonomy, I suggest that a full consideration of relational autonomy and of the materiality of relationships is in order. While relational autonomy is not new to discussions in medical ethics [16], it has not been sufficiently applied to debates in organ donation. Furthermore, relational autonomy needs to be considered alongside an ontology of relationships that takes embodiment seriously.

Relational autonomy does not deny the importance of informed consent, but it broadens the notion to include one's close relations as shared decision makers. A person's community can also be deeply affected by their medical decisions. Close relations may offer new perspectives that make a decision more robustly informed. It is clear that both these points are true the case of organ donation. The family is directly affected by the decisions made in a way that the decedent is not. Their grief process will be affected by the decision to donate the organs of their loved one or not. They are informed stakeholders in the situation. Furthermore, the family can be informed about the current situation in a way the decedent could not have been – they are aware of the state of the body, of their familial needs and of other medical and social particularities.

An easy response to this is that those on the transplant list are affected more radically by the decision to donate than the family. They need the body more. However, to prioritize this need is to reduce a corpse to a set of parts, rather than a remnant of a humanly embodied life – a life in relationship. For this reason, the enduring materiality of the filial relationship needs to be considered as well as relational autonomy.

The family has actively participated in the life of the person in an emotional, mental and physical sense and thus has a special kind of claim on their deceased body. Instead of conceiving of bodies as separate, individualized entities, human bodies should be thought of as deeply connected through relationships. Relationships have physical effects and the physical affects relationships – such an ontology

recognizes that family members contribute to the physical being of one another.

Following this line of thought, at least three reasons can be identified for why families have enduring, relational claims on the body of their loved one. First, they have invested in that body in a way that has shaped its being. Not only is this true for physical care such as feeding or bathing, but also for emotional care. Family members comfort each other, offering social and emotional supports that have real effects on health. Numerous studies demonstrate that close social bonds are associated with longer life spans, faster recovery rates, and improved cardiovascular health, among other benefits [17]. If there are healthy organs to donate, it may be partially due to the familial, social bonds enjoyed by the decedent. The family has invested in the body and thus has likely influenced the body's physical make-up. Family members are deeply ontologically interrelated even if they are not genetically related.

Second, the body served as the site of relationship with that person. Death does not mean the body suddenly loses relational meaning – the arms that hugged, the eyes that wept and the heart that quickened are all still present after death. Though the person is no longer present, the family still carries relational and emotional ties with the body of the deceased. Gillian Hadow demonstrated this phenomenon in her sociological research on organ donation. Hadow interviewed family members who had decided to donate the organs of their loved one, concluding that "organ transplantation is dependent on the death of the body, but death does not mean the termination of the relationship with the previous embodied self" [18]. In other words, the relationship is still present to the family in the form of the bodily remnants of the person.

Third, as mentioned above briefly, the family will be affected by how the bodily remains are distributed. The decision to donate may affect the funeral proceedings one way or another and can certainly impact the grieving process. If donation ensues, many family members sense an enduring attachment to the donated body parts or organs. For instance, Hadow interviews one woman who asks that her son's organs stay in Scotland "because I do not want ever to go to Bristol thinking somebody is walking about here with David's heart. I hate Bristol. I'm not going back there" [18]. Similarly, in her book *A life everlasting*, Sarah Gray details her and her husband's journey to the medical facilities that use their late son's body parts for research [19]. They travel the United States in order to meet the technicians that have interacted with their son's cells, liver, and eyes. Their commitment to this journey is telling of how deeply they were affected by their son's donation. While this was a helpful process for the Gray's, it may not be the best choice for every family and needs to be considered within the particular circumstances. Either way, it is clear that organ donation decisions have a profound effect on families.

Once both relational autonomy and relational ontology are considered, it follows that families have a special claim on the body of their loved one. They themselves have affected the body and will continue to be affected by it. After their loved one dies, they maintain the closest sense of identification and belonging with the body. They are stakeholders. Because of this, families should be afforded the

ability to refuse organ donation. Overriding family wishes violates the filial relationship with the dead body.

The double veto

Is it possible to respect the filial relationship with the body while also respecting the decedent's prior wishes regarding organ donation? Yes, so long as both parties have the option to refuse organ donation — T. M. Wilkinson argues that a double-veto position can be consistently held in regard to organ donation. Such a position entails "that the individual's refusal should override family's wish to donate, while the family's refusal should override the individual's wish to donate" [12]. Rather than considering either the decedent's or the family's decision decisive over and against the other, the double-veto system gives both parties some decision making power.

As he argues, this system works if one conceives of organ donation as a negative right. In other words, people have a right to refuse that their organs be donated, but consent to organ donation does not entitle an individual to a guarantee of donation. It would be strange to construe donation as a positive right — organs are often unsuitable for transplant or cannot be extracted effectively at death. In registering as a donor, one offers their organs, but we would not say that their rights are violated if the offer is not accepted. "Since rights are correlative to duties, the deceased could only have a positive right to have her offer accepted if others had a duty to the deceased to accept the right. They do not have the duty" [12]. Consent to organ donation does not impose a duty on others to carry out donation and it would be odd to think of the opportunity in such a way.

Thus, organ donation is best understood as a negative right, which in turn makes the double-veto position coherent. Families should be afforded this negative right on the basis of their familial, relational claims on the body. The individual should also be afforded this negative right for a few reasons. Though the arguments for allowing the decedent's autonomy to be decisive after death are problematic, organ donation can also affect someone in life. Most importantly, as Iltis points out, donor status often implies premortem interventions and access to medical records [10]. There are also good consequentialist reasons to respect refusals to donate, as this promotes trust in the medical establishment and in organ donation practices in general. Furthermore, some refuse donation for religious reasons — respecting such a refusal can be a matter of respecting a particular religious tradition [20]. Because of this, families should not wield all the decision-making power. They should not be able to authorize donation when the decedent had clearly refused.

Conclusion

The trend in the literature on organ donation has been to suggest the adjustment of consent practices in favour of increased organ donations, rather than to reflect on the difficult question of who can rightfully make decisions about a dead body. Such reflections lead to a consideration of the embodied, relational ties the family shares with the

decedent. I have argued that appeals to utilitarian reasoning, and appeals to the autonomy of the decedent, by analogy to medical informed consent or to wills, do not neatly apply to organ donation. A different approach is needed which takes relational autonomy and embodied nature of filial relationships into consideration. The family has a special claim on the body — they have invested in that body, it has served as the site of relationship with that person and they will be affected by how the bodily remains are distributed. Furthermore, the family is better informed than the decedent in the sense that they are within the context of a potential donation. For these reasons, a double-veto system is the best means of respecting both the potential donor and the family members as decision-makers in cases of organ donation.

Disclosure of interest

The author declares that she has no competing interest.

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