Against the family veto in organ procurement: Why the wishes of the dead should prevail when the living and the deceased disagree on organ donation

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Abstract

The wishes of registered organ donors are regularly set aside when family members object to donation. This genuine overruling of the wishes of the deceased raises difficult ethical questions. A successful argument for providing the family with a veto must 1) provide reason to disregard the wishes of the dead and 2) establish why the family should be allowed to decide. One branch of justification seeks to reconcile the family veto with important ideas about respecting property rights, preserving autonomy, and preventing harm. These arguments are ultimately unsuccessful. Another branch of arguments is consequential, pointing out the negative consequences of removing the veto. Whether construed as concerning family distress or a potential drop in the organs available, these arguments are unsuccessful; the first fails to recognize the tremendous distress associated with waiting for an organ, while the second has little supporting evidence. A final section considers and rejects whether combining some of these arguments could justify the family veto. We should thus remove the family veto in organ donation.

Keywords: autonomy of the dead; family refusal; family veto; first person authorization; organ donation; organ procurement; organ transplantation

Introduction

Should the family of a registered organ donor hold veto power, allowing them to block the removal of organs for transplantation? While such a *family veto* is often considered a creation of the medical profession,[1] its ethical permissibility has been questioned.[2] Others have called for increased attention to family refusal.[3] This article assesses the permissibility of the family veto in cases of genuine conflict between the deceased registered donor and the family; that is, it addresses cases where we have every reason to believe that the deceased registered donor wanted to donate and the family opposes doing so. As adhering to the wishes of the family would represent a family overrule in a situation of genuine conflict, such overrules will be termed *genuine overrule*.

The question of genuine overrule does not exhaust the interesting discussions to be had regarding the role of the family in organ donation. One such discussion is the role of the family when the deceased was undecided about donation. Another is what options the family should have[4] if they believe that the deceased's donor registration does not adequately reflect the real preferences of the deceased because they had changed their mind regarding organ donation without correcting their donor status.[5] While important, these discussions are different from the subject of genuine overrule. If, as this article argues, the arguments for allowing genuine overrule are unconvincing, the family could—and perhaps should—retain a pivotal role in the organ procurement process. For example, we can reject genuine

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[1] *The Stanford Encyclopedia of Philosophy (Winter 2016 Edition)* (2011) s.v. 'The donation of human organs' (T.M. Wilkinson, & S. Wilkinson).

[2] Bramstedt, K. A. (2013). Family refusals of registered consents: The disruption of organ donation by double-standard surrogate decision-making: Vetoing family refusals. *Intern Med J*, 43(2): 120–123: 120–123; Kmietowicz, Z. (2013). Doctors should defend the wishes of patients on the organ donor register more 'robustly'. *BMJ*, 346(apr12 2): f2357–f2357: f2357–f2357; May, T., et al. (2000). Patients, families, and organ donation: who should decide?. *Milbank Q*, 78(2): 323–336: 323–336; Veatch, R. M., & Ross, L. F. (2012). *Transplantation ethics*. Washington, D.C.: Georgetown University Press; D. Shaw. We should not let families stop organ donation from their dead relatives. *BMJ*, 345(aug07 1): e5275–e5275: e5275–e5275; Shaw, D., et al. (2017). Family over rules? An ethical analysis of allowing families to overrule donation intentions:. *Transplantation*, 101(3): 482–487: 482–487.

[3] Johnson, R. J., et al. (2014). Organ donation and transplantation in the UK—The last decade: A report from the UK National Transplant Registry. *Transplant J*, 97: S1–27: S1–27; Mulvania, P., et al. (2014). Successful international collaboration improves family donation conversations resulting in increased organ donation. *Transplant Proc*, 46(6): 2058–2065: 2058–2065.

[4] I owe this point to an anonymous reviewer.

[5] Shaw, D. M. (2016). The consequences of vagueness in consent to organ donation: The consequences of vagueness in consent to organ donation. *Bioethics*: 426.

overrule but still consult the family when the deceased had not registered a decision. We can also reject genuine overrule but still allow the family to provide evidence that the deceased did not ultimately want their organs removed despite having registered as a donor on an earlier occasion.

To what extent is genuine overrule a substantial problem which affects donation rates? The first thing to note is how prevalent it is in current practices to allow families to overrule a registered wish to donate, as demonstrated by a recent survey of the role of the family in 52 procurement systems. The study reports that 19 of the 25 nations with presumed consent systems provide a method for individuals to register as donors. In only four of these nations, the family cannot veto the deceased's explicit wish to donate.[6] Similarly, in 25 of the 29 opt-in nations, the family must consent before the wishes of registered donors are carried out.[7] In a similar vein, WHO's *Guiding Principles on Human Cell, Tissue and Organ Transplantation* observes a reluctance across various procurement systems to act on a wish to donate if the family objects.[8] This veto right is not merely a possibility; it is often utilized. The proportion of family refusals in situations where the deceased is a registered donor in various countries illustrates this: Australia 24%,[9] United Kingdom 14%,[10] and Canada 20%.[11] Importantly, as Shaw stresses, not every such refusal is a genuine overrule;[12] the family could merely be correcting a mistake.[13] To assess the proportion of genuine overrules, we can consider NHS's register of the reasons families provide for overruling. According to the UK Donation Ethics Committee, we can divide these reasons into three main categories: New

[6] Rosenblum, A. M., et al. (2012). The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: An analysis of 54 nations. *Nephrol Dial Transplant*, 27(6): 2533–2546: 2541.

[7] Ibid. For similar conclusions, see Janssen, A., et al. (2004). Consent systems for post mortem organ donation in Europe. *Eur J Health Law*, 11(2): 175–186: 175–186; Neades, B. L. (2009). Presumed consent to organ donation in three European countries. *Nurs Ethics*, 16(3): 267–282: 267–282.

[8] WHO. (2010). WHO guiding principles on human cell, tissue and organ transplantation. *Transplantation*, 90(3): 229–233: 2.

[9] Ministry of Health New Zealand. (2016). *Review of deceased organ donation and transplantation. Ministry of Health*: 52.

[10] NHS Blood and Transplant. (2016). Families saying no to donation results in missed transplant opportunities for UK patients.

[11] Toews, M., & Caulfield, T. (2016). Evaluating the 'family veto' of consent for organ donation. *Can Med Assoc J*, 188(17–18): E436–437: E436–437.

[12] Shaw, *op. cit.* note 5: 426.

[13] Shaw develops this point in Shaw, *op. cit.* note 5.

evidence of refusal (9.6%), reassessment of overall benefit (31.6%) and genuine overrule (46.5%).[14] These numbers substantiate the relevance of discussing the permissibility of genuine overrule by the family.

This article examines and rejects several possible arguments for maintaining the family veto in cases of genuine overrule. In conducting this discussion, the article artificially assumes that the family agrees amongst themselves when they disagree with the deceased's registered wish to donate. This assumption is for reasons of clarity and to ensure that the described situation is one in which there is the most persuasive case for following the family's wishes.[15]

The examined arguments in favor of the family veto fall in two different categories: One identifying a specific value or approach that could provide us with reasons to keep the family veto and another pointing to adverse outcomes associated with removing the veto. The first section is dedicated to the first kind of argument and addresses arguments that seek to reconcile the veto with the important values of property, preventing harm, and preserving autonomy. The second part addresses consequentialist arguments, which point out the negative consequences of removing the family veto. The negative consequences examined here are distress to the family and a drop in the number of organs available for transplantation. A final section assesses and rejects whether arguments from autonomy, harm, and distress to the family in combination might provide a successful argument for the family veto. The extent to which such arguments can justify the family veto is analyzed and ultimately rejected.

The standard of assessment employed here is that for an argument for the family veto be successful (and complete), it must accomplish two things: it must provide reason to disregard the wishes of the deceased and reason to locate the decision-making with the family. The article thus begins with the widely shared assumption in medical ethics that we have reason to respect the decisions that the deceased person made while alive.[16] This approach is often based on the importance of respecting personal autonomy and is the basis

[14] UK Donation Ethics Committee. *Involving the family in deceased organ donation*. Academy of Medical Royal Colleges: 27.

[15] For a good overview over these complexities, see UK Donation Ethics Committee, *op. cit.* note 14.

[16] Childress, J. F. (1997). The normative principles of medical ethics. In Veatch, R. M., ed. *Medical ethics. Jones and Bartlett series in philosophy*: 29–55; Taylor, J. S. *Practical autonomy and bioethics*. Routledge; Medical ethics. Jones and Bartlett series in philosophy.

for many discussions of various procurement systems.[17] In this light, it examines whether various arguments provide reason to ignore these reasons and reason to allow the family to conduct a genuine overrule.

The rightness of keeping the family veto

Property: Organs as inherited property

Could an argument based on strong ownership to one's own body justify the family veto? The idea here is that while we have strong ownership over our bodies in life, our property (including our organs) passes on to our family after death. This would extend the strength of family property rights over organs from their current status as quasi-property rights.[18] While considering organs as property is controversial,[19] some suggest it as a viable framework for discussing organ procurement.[20]

Initially, an argument based on the passing of property is structurally well suited to fulfilling the two requirements for a successful argument. We disregard the wishes of the deceased because whatever right that person had to their property now resides with the family. As the family inherits the organs and the rights accompanying them, the property-based argument also provides reason to let the family decide. It therefore also seemingly fulfills the second criteria.

The first problem with this argument is that the transaction of rights just described differs from how the family veto functions. If all of the deceased's rights over their

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[17] MacKay, D., & Robinson, A. (2016). The ethics of organ donor registration policies: Nudges and respect for autonomy. *Am J Bioeth*, 16(11): 3–12: 3–12; Saunders, B. (2012). Opt-out organ donation without presumptions. *J Med Ethics*, 38(2): 69–72: 69–72; Saunders, B. (2012). Opt-out donation and tacit consent: a reply to Wilkinson and De Wispelaere. *J Med Ethics*, 38(2): 75–76: 75–76; De Wispelaere, J. (2012). Tacitly opting out of organ donation: Too presumptuous after all?. *J Med Ethics*, 38(2): 73–74: 73–74; Veatch & Ross. (2011). *op. cit.* note 2; *The Stanford Encyclopedia of Philosophy (Winter 2016 Edition)* s.v. 'The donation of human organs' (Wilkinson M., & Wilkinson S.); Wilkinson, T. M. *Ethics and the acquisition of organs*. Issues in biomedical ethics.

[18] Peterson, K. E. (2005). My father's eyes and my mother's heart: The due process rights of the next of kin in organ donation. *Val UL Rev*, 40: 169: 185; Price, D. P. T. (YEAR). *Legal and ethical aspects of organ transplantation*. Cambridge [England]: New York: University of Cambridge; Cambridge University Press: 127.

[19] Kamm, F. M. (YEAR). *Death and whom to save from it*. Morality, mortality Kamm F. M.; Vol. 1: 211.

[20] Voo, T. C., & Holm, S. (2013). Organs as inheritable property?. *J Med Ethics*, medethics-2013: medethics-2013.

organs are transferred to the family, these rights include more than the right to block donation against the wishes of the previous owner of the organs. Before dying, the deceased also possessed the right to donate. Therefore, if the deceased's rights over their organs pass on to the family, the family should also be allowed to donate *against* the wishes of the deceased. For these reasons, the property-based argument cannot ground the family veto in its current construction but instead suggests an expanded version.

There is, however, a more fundamental problem with the property-based argument. The above description of the passing of property rights is in disaccord with how relatives usually inherit property rights. Property and the rights associated with it do not transfer in an unmediated manner. When property passes to the family, we generally allow the deceased to influence this process through the formulation of a will. Thus, if organs are property, it does not provide us with reason to ignore the wishes of the deceased; on the contrary, thinking about organs as property adds support to the idea that the deceased should have the final say in the fate of their organs. For current purposes, we can at the very least conclude that thinking about organs as property does not provide us with reason to uphold the family veto in situations of genuine conflict. It neither provides us with reason to ignore the wishes of the deceased nor reason to let the family decide.

Harm: Dead people cannot be harmed

The family veto might be plausible because it does not harm the deceased when the family vetoes their wish to donate; If we cannot harm the dead, then allowing families to decide does not harm the dead. While there is considerable literature trying to demonstrate the plausibility of posthumous harm,[21] these metaphysical issues will be set aside here. Instead, this section examines the extent to which the truth of the claim that we cannot harm the dead supports a family veto.[22]

Concerning the two criteria for a successful argument for the family veto, it seems as though if we cannot harm the dead, this provides us with reason to disregard their

[21] Benziman, Y. (2016). Dead people and living interests. *Mortality*, 1–12: 1–12; Hamer, C. L., & Rivlin, M. M. (2003). A stronger policy of organ retrieval from cadaveric donors: Some ethical considerations. *J Med Ethics*, 29(3): 196–200: 196–200; Taylor, J. S. (YEAR). *Death, posthumous harm, and bioethics*. New York [u.a.: Routledge; Wilkinson, *op. cit.* note 17; Wilkinson, T. M. (2007). Individual and family decisions about organ donation. *J Appl Philos*, 24(1): 26–40: 26–40.

[22] Note that among those who deny that we can harm the dead, several maintain that we have other reasons to follow their wishes; Benziman, Y. *op. cit.* note 21: 10; Taylor, *op. cit.* note 21: 67.

wishes. The truth of the claim that we cannot harm the dead seemingly fulfills the first criteria. If we do not harm the dead when we disrespect their wishes, we would have reason to set aside the deceased's registered wishes regarding organ donation. However, following the presented criteria for a successful argument, we also need reason to let the family make the decision.

For an argument concerned with harm, it is interesting to consider whether we may have harm-based reason to let the family decide. Initially, it should be acknowledged that it removes one harm-related problem; that letting the family decide does not harm the dead. Presumably, however, an argument concerned with harm is interested in more than whether the dead are harmed. We should also consider the harm inflicted on the living by various procurement policies. Harris reminds us that in considering different organ policies, we should take into account the interests of those who are eagerly waiting for a transplant to prolong their time among the living.[23] While consequential arguments will be assessed later, acknowledging the harmful consequences of different policies offers an interesting perspective on the debate over harm. Even if we cannot harm the dead, we may readily worry about practices that are likely to harm the living. Consideration of harm shows that even if we cannot harm the dead, this does not provide us with reason to let the family decide. This is even truer if keeping the family veto involves considerable harm to the living.

Respecting autonomy

Another possible problem with the family veto pertains to the autonomy of those who had registered a wish to donate: The family overruling the decision to donate infringes on the autonomy of the registered donor.[24] Zambrano has recently offered a novel argument for the opposite conclusion; that we should understand registering as a donor as if the person consents to let the procurement system remove their organs for transplantation.[25] From this plausible interpretation, Zambrano argues for what he terms the non-removal thesis. This thesis is that not removing the organs of the registered donor is not in any way objectionable

[23] Harris, J. (2003). Organ procurement: Dead interests, living needs. *J Med Ethics*, 29(3): 130–134: 133. In Harris' view, we can acknowledge that dead people have interests, but this also holds for the living, and the interests of the living seem to be of a different character, which should be given more weight.
[24] Veatch, & Ross, *op. cit.* note 2: 136.
[25] Zambrano, A. (2017). Patient autonomy and the family veto problem in organ procurement. *Soc Theory Pract*, 43(1): 180–200: 190.

in terms of autonomy.[26] Zambrano understands autonomy roughly as self-rule,[27] but little hinges on this specification. He argues for the truth of the non-removal thesis through a series of analogous cases, each of which seeks to demonstrate how in a case similar to organ donation, autonomy is not infringed upon if the registered wish to donate is not carried out. Zambrano describes a case in which a person (X) consents to let another person (Y) use a car (A) for whatever purpose. The family of X (Z) is against this. One day, X could use the car to bring a very ill person (W) to the hospital but decides not to do so. Not utilizing the car results in W's death. According to Zambrano, this is analogous to the organ donation case. There, X consents to let the organ procurement system (Y) utilize his organs (A) for transplantation. The family (Z) is against this. While the procurement system could utilize the organs to save the life of a person (W), they choose not to do so. Both cases share the following structure:

1) X consents that Y utilizes object A

2) Person Z expresses the preference that Y does not utilize A

3) At some point, Y can utilize A to the benefit of person W. X considers the possibility but decides not to utilize A.

4) As a consequence of Y's decision, W dies.

Zambrano's argument is an argument from analogy. It describes a case that is structurally similar to the family veto case, concluding that if there is no infringement of autonomy in the former case, then the same holds for the organ donation case. The general principle behind this verdict is that it is not a right for a person that someone utilizes what the first person has consented or authorized that they use. Thus, when transplant clinic doctors go against the wishes of the person who consented to donate because of family members' preferences against donation, no one has done anything morally wrong (regarding autonomy). If the non-removal thesis is correct, how far does it get us in terms of justifying the family veto?

Consider again the two criteria for a successful argument in favor of the family veto. As with the question of harm, it is intuitively the case that if ignoring the wishes of the dead does not frustrate their autonomy, then we are provided with reason to disregard the deceased's wish to donate. However, we may have reason to doubt that the truth of the non-

[26] Ibid.: 182.

[27] Ibid.: 191.

removal thesis provides us with any reason to let the family decide; that is, we may have reason to doubt that it fulfills the second criterion. This is the case for the following reason: The truth of the claim that the registered donor's autonomy is not compromised if their family's preferences against donation are followed relies on the truth of a much broader thesis; that the registered donor's autonomy is not compromised if for whatever reason their consent to donation does not result in their organs being removed. If the doctors introduce a 'heads only' policy, where a coin flip decides whether the organs of a potential donor are utilized, the autonomy of those potential donors is not infringed; or rather, if the correct view of autonomy is one in which autonomy is not infringed in the car case and in the family veto case, then the same must hold in these cases. In most of Zambrano's cases, the person who objects does so for some particular—albeit not very important—reason. However, on the truth of Zambrano's account, the reasons provided can be of whatever quality and importance. This is not a critique of the non-removal thesis but rather a demonstration of the limits of what it shows, should it be true; that providing the family with a veto does not infringe on the autonomy of the registered donor and cannot establish that the family should have such a veto, as we could also provide others with the decision-making capacity without infringing on the autonomy of the registered donor. The truth of the non-removal thesis does not support the privileged position given to the preferences of the family under current family veto practices. Consequently, the argument is incomplete in the sense that its truth would only establish parts of what is needed to uphold the family veto. It does not, after all, provide us with a positive reason to have a formal arrangement where the preferences of the family take priority.

Relational autonomy

There is a somewhat different argument, which offers an autonomy-based reason for keeping the family veto. These arguments, prominently developed in various ways by Boddington and Johnston,[28] analyzes a broader, more inclusive understanding of autonomy. For Johnston, the upshot of this is that the family should have veto over whether the wishes of the deceased regarding donation are carried out. While each article offers many novel and interesting perspective, I address here only the claims relevant for the problem at hand.

[28] P. Boddington. Organ donation after death—should I decide, or should my family?. *J Appl Philos* 1998; 15(1): 69–81: 69–81; Y. Johnston. Donation decisions after death: The case for a family veto. *Ethics Med Public Health* 2017; 3(4): 486–92: 486–92.

Johnston argues that there are three reasons, why the family have enduring, relational claims on the body of their deceased relative.[29] The first is that the family have invested physical and emotional care in the deceased while the person was alive. Secondly, the body of the deceased served as the site of the relationship. It retains, according to Johnston, a special meaning for the family. Thirdly, the family is profoundly affected by how the remains of the deceased is treated. Taken together, Johnston believes these three elements to provide that the underpinnings, of a special relationship between the family and the body of their deceased relatives. Not providing them with a veto 'violates the filial relationship with the dead body.[30] How far does the idea of relational autonomy take us, in terms of supporting the family veto. If we grant that such a broader conception of autonomy is valuable and plausible it does provide us with reason to overrule the wishes of the deceased. The problem is however, that arguments such as that outlined above, faces the difficulty of placing the veto power with the family. The problem arises because many people could have had relationships with the deceased, which corresponds to the elements Johnston takes to create such a special relationship. Careers, co-workers, neighbors, former spouses and life-long friends may in many cases fulfill the criteria for a special relationship. In some instances, perhaps even more so, than family members. Perhaps regrettably, not everyone have a close relationship with their parents and siblings. For these reasons it seems reasonably to conclude, that even this broader account of autonomy, cannot provide reason to uphold a family veto.

The negative consequences of removing the family veto

The above section concluded that perspectives rooted in the value of not harming, preserving autonomy, and respecting property did not provide us with convincing reason to keep the family veto and allow genuine overrule. This section offers a different perspective, with a focus on the negative consequences associated with removing the veto. There are two versions of the negative consequence argument, one pointing to the *distress* experienced by the family, the other maintaining that removing the family veto could result in *fewer organs* donated. This section presents these distinct versions and evaluates how and to what extent they can uphold the family veto.

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[29] Johnston (cited n. 28) : 490.
[30] Ibid. : 491.

Family distress

Some suggest that we should keep the family veto on the grounds that removing it would place a tremendous burden on the deceased's family. Thus, removing the family veto may ultimately render a difficult situation even harder for those who are left behind. This suggestion has featured prominently in discussions of the family veto.[31] For example, Den Hartogh, who rejects that the family veto is as such justified, considers this the best reason to retain it.[32] Does minimizing distress provide us with reason to keep the family veto? Initially, family distress is a promising candidate when we consider the already established criteria for what a successful argument for the family veto should achieve. If employing the family with a veto minimizes distress, the argument supplies both reason to disregard the wishes of the deceased and reason to let the family make this decision.

To some extent, it is an empirical question whether maintaining the family veto is the best way of minimizing family distress. Might family distress possibly be minimized by not asking the family at all?[33] Or, as Wilkinson suggests, is it possible to minimize distress by providing less information to the family than what their informed consent requires?[34] Others point out how having a veto may in itself be harmful to the family.[35]

A more fundamental concern with the distress argument is that once we scrutinize it, it is unable to show why the family should be allowed to hold a veto. Even if we grant that keeping the family veto will result in less distress for the family, this is insufficient to conclude that we have a distress-based argument for keeping the family veto. If we care about distress, we should care about everyone distressed by the existence or removal of the family veto. What other sources of distress could outweigh that of the family? Consider those who are waiting to receive an organ and their families. Assuming that the family veto results in fewer organs, some on the waiting list and their families experience a prolonged waiting period before receiving a transplant. Others on the waiting list are affected even more

[31] Wilkinson, T. M., *op. cit.* note 21: 26–40; Wilkinson, T. M., *op. cit.* note 17: 67; De Wispelaere, J., & Stirton, L. (2010). Advance commitment: An alternative approach to the family veto problem in organ procurement. *J Med Ethics*, 36(3): 180–183: 180–183.

[32] den Hartogh, G. (2012). The role of the relatives in opt-in systems of postmortal organ procurement. *Med Health Care Philos*, 15(2): 195–205: 204.

[33] Richards, J. R. (2012). *The ethics of transplants: Why careless thought costs lives*. Oxford; New York: Oxford University Press: 173.

[34] Wilkinson, T. M., *op. cit.* note 17: 68.

[35] Shaw, *op. cit.* note 5.

profoundly because the family veto results in fewer organs, some ultimately dying as a result. Weighing up the distress of these different groups is no easy task. The conservative conclusion, sufficient for our purposes here, would be that a distress-based argument does not provide us with clear reason to keep the family veto. Would it be plausible to suggest that the concerns regarding distress point toward removing the veto? I believe it would. Each veto decision means that, on average, 3-4 people who would have received an organ at that point must wait longer. Waiting is a source of distress, also for the relatives of those who wait. Dying and losing a close relative is also clearly distressing. Contrary to the distress of the families without a family veto, little can be done to minimize the kinds of distress resulting from a family veto. As each veto decision means that, on average, 3–4 people who would have received an organ do so later (or not at all), the family veto imposes tremendous distress on a large group of people. It might therefore be reasonable to suggest that the distress-based argument, adequately specified, actually goes against the family veto.

Fewer organs

A different consequentialist approach takes its starting point in the concern for those in dire need of a transplant, arguing that while the family veto may have the direct consequence that some organs are not utilized, the veto should be kept in place because removing it would result in a net drop in the organs available for transplantation. Wilkinson suggests that such a reason is 'probably a good one'.[36] We can imagine a number of mechanisms which could lead to such a result.[37] Perhaps stories of how family objections are overruled can lead to general mistrust and lower donation rates.[38] Perhaps people will fear that their family cannot protect them against a medical system overly focused on acquiring organs.[39] Perhaps bad experiences will deter the family members from becoming donors themselves. These

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[36] Wilkinson, T. M., *op. cit.* note 17: 79.

[37] Bird, S. M., & Harris, J. (2010). Time to move to presumed consent for organ donation. *BMJ*, 340(may04 1): c2188–c2188: c2188–c2188; Wilkinson, T. M. (2005). Individual and family consent to organ and tissue donation: is the current position coherent?. *J Med Ethics*, 31(10): 587–590: 587–590.

[38] Skwirczyńska-Szalbierz, E., et al. (2014). Communication with family after loss, in the context of transplantology. *Transplant Proc*, 46(6): 2036–2039: 2036–2039.

[39] Naylor, C. D. (1989). The role of the family in cadaveric organ procurement. *Ind LJ*; 65: 167: 186.

and similar mechanisms are suggested in the literature as giving us such consequential reasons to keep the family veto.[40]

These claims are empirical and address what may happen if we remove the family veto. Focusing on the number of organs available means that the reason offered for keeping the veto is similar to the argument of those who propose removing it. The question at hand is thus not which procurement system brings about the most organs while also fulfilling other goals to which the family veto caters (e.g., family distress or family property rights). Whether to keep or remove the family veto depends on the number of organs each solution yields. This kind of argument is therefore structurally well suited to fulfilling the identified criteria for a successful argument for the family veto. If its empirical assertions hold, it provides us at the same time with reason to set aside the wishes of the deceased and to let the family have a veto.

Three kinds of experiences may be useful in our assessment of the strength of such an argument: public opinion regarding the family veto, experiences with removing or limiting the family veto, and knowledge about what affects family decisions. This can serve as important inspiration as to how family refusals may be reduced.

Public opinion regarding the family veto is relevant in this context because it provides us with information about how likely people are to react negatively toward a procurement system that allows the wish to donate to prevail over family objections. The few available studies indicate that the majority of people do not believe the family should be allowed to veto the decision to donate.[41] For instance, a Canadian study showed that 89% of the public holds this view.[42] In the United Kingdom, a survey of 2,072 adults asked, '*Do you think that after you've died your next of kin should be able to overrule your decision to be an organ donor?*' To this question, 11% responded yes, 73% no, and 16% 'don't know'.[43] We do not know whether people hold these views only in situations of genuine conflict. Furthermore, we must admit that many of the mechanisms described as possible avenues

[40] Klassen, A. C., & Klassen, D. K. (1996). Who are the donors in organ donation? The family's perspective in mandated choice. *Ann Intern Med*, 125(1): 70–73: 70–73; Truog, R. D. (2008). Consent for organ donation — Balancing conflicting ethical obligations. *N Engl J Med*, 358(12): 1209–1211: 1209–1211; Wilkinson, T. M., *op. cit.* note 17: 79. Wilkinson, T. M. op. cit. note 40
[41] Spital, A. (1996). Mandated choice for organ donation: time to give it a try. *Ann Intern Med*, 125(1): 66–69: 66–69.
[42] Downie, J., et al. (2008). Family override of valid donor consent to postmortem donation: Issues in law and practice. *Transplant Proc*, 40(5): 1255–1263: 1255–1263.
[43] NHS Blood and Transplant, *op. cit.* note 10.

for a net drop in organs relates to emotional reactions. Whether people will have an emotional reaction to a removal of the family veto is hardly something we can assess from these numbers. However, the numbers indicate that the public support for the family veto is limited.

Furthermore, we may point to actual experiences with removing the family veto. Veatch points out that the United States has continuously sought to pass and implement legislation that gives the wishes of the registered donor priority over their relatives.[44] The 2006 revision of The Uniform Anatomical Gift Act introduced a specific section on the family veto.[45] This section introduced the concept of first-person donation, once again strengthening the legal responsibilities to carry out the wishes of the donor.[46] Surveys of procurement clinics show that this has led to a decline in Organ Procurement Organisations (OPOs), which allow the family to veto donation.[47] While some worry that such practices might lead to lawsuits, these fear seems not to have materialised. Based on the last ten years, a 2014 study of LifeSource, an OPO which covers Minnesota, South Dakota, and parts of Wisconsin, concluded that 'Fears of legal action and adverse media coverage are unfounded'.[48] The Center for Organ Recovery and Education (CORE) program which operates in Pennsylvania, New York, and West Virginia, provides a small sample. Here, the family is informed of the deceased's decision to donate, and they are offered counseling and support should they disagree.[49] Despite initial fears that this would lead to lawsuits, such fears never transpired.[50] A broad and recent study further adds to the confidence we could have in policies giving priority to the wishes of the deceased. It concluded that 'the enactment of First Person Authorization legislation increases the likelihood of familial

[44] Veatch, & Ross, *op. cit.* note 2: 136–37.
[45] Veatch, & Ross, *op. cit.* note 2.
[46] Ibid.
[47] Chon, W. J., et al. (2014). When the living and the deceased cannot agree on organ donation: A survey of US organ procurement organizations (OPOs). *Am J Transplant Off J Am Soc Transplant Am Soc Transpl Surg*, 14(1): 172–177: 172–177; Veatch, & Ross, *op. cit.* note 2: 137.
[48] Stahler, P. A., et al. (2014). Honoring patients' organ donation decisions when family conflict is present: Experience from a single organ procurement organization. *J Trauma Acute Care Surg*, 77(4): 555–558: 555–558.
[49] Downie, *et al., op. cit.* note 39: 1255–1263.
[50] Ganikos, M. (2010). Organ donation: An overview of the field. In Siegel, J. T., & Alvaro, E. M., eds. *Understanding organ donation: Applied behavioral science perspectives*. Chichester, U.K.; Malden, MA: Wiley-Blackwell: 24.

authorization and satisfaction with the final donation outcome'.[51] While family distress has been rejected as a reason for keeping the family veto, a policy which makes it easier on the family and seemingly prompts family discussion regarding donation is undoubtedly a good thing.

Wales provides another recent experience. There, efforts to limit family influence in situations of genuine conflict have accompanied the introduction of an opt-out procurement system. While this system allows the family to present evidence that the deceased did not want to donate, it is not enough that the family would prefer that the organs are not removed.[52] It is important to note that the family can in fact still overrule in genuine conflict situations provided that their protests are very strong.[53] Welsh law can nevertheless be said to involve a limiting of the influence of the family in situations of genuine conflict. In terms of family refusals across all categories, Wales has made improvements under the new legislation and is currently the country doing best in the UK.[54] In terms of the number of organs available, the signs are mixed but positive. In the first year since the introduction of the new legislation, there was a slight drop,[55] but the current numbers are better than before the legislation.[56] Together, this suffices as further indication that reducing family influence will not result in fewer organs.

Based on the available evidence, we cannot accept the fear of fewer organs as a decisive reason for keeping the family veto. Our available experiences with limiting family influence do not sustain the fear that fewer organs will be available to help those in need of

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[51] Traino, H. M., & Siminoff, L. A. (2013). Attitudes and acceptance of first person authorization: A national comparison of donor and nondonor families. *J Trauma Acute Care Surg*, 74(1): 294–300: 294–300.
[52] National Assembly for Wales. *Human Transplantation (Wales) Act 2013*.
[53] Douglas, J. F., & Cronin, A. J. (2015). The Human Transplantation (Wales) Act 2013: An act of encouragement, not enforcement: The Human Transplantation (Wales) Act 2013. *Mod Law Rev*, 78(2): 324–348: 324–348; Human Tissue Authority. *Code of Practice on the Human Transplantation (Wales) Act 2013 May 2014*.
[54] NHS Blood and Transplant. (2018). *Organ donation and transplantation activity report 2017/18*: 133; Welsh Government. *Wales leading on organ donation consent rates*. Available at: https://gov.wales/newsroom/health-and-social-services/2018/consentrate/?lang=en [Accessed 3 December 2018].
[55] Albertsen, A. (2018). Deemed consent: Assessing the new opt-out approach to organ procurement in Wales. *J Med Ethics*, 44(5): 314–318: 314–318; NHS Blood and Transplant. *Organ donation and transplantation activity report 2015/16*; V. Young, et al. *Evaluation of The Human Transplantation (Wales) Act: Impact evaluation report*. Welsh Government and Social Research.
[56] NHS Blood and Transplant, *op. cit.* note 51.

a transplant. While the evidence available is sparse, it should be enough to dispel the idea that the fear of fewer organs is a clear-cut argument against removing the family veto.

A final observation is possible. Even if we accept that removing the family veto comes with the possible net drop in organs, such an argument for the family veto is limited. The argument automatically commits anyone who proposes it to endorse initiatives which effectively lower family refusal rates. If against the presented evidence, the empirical premise of fewer organs is true, we would not only be committed to keeping the veto but also to ensure that the family refusal rates are minimized. This would include initiatives to expose the family to discussions about a wish to donate before the death of the potential donor.[57] Another aspect is about improving knowledge and understanding of the brain-dead criteria.[58] Experiences from Spain and Australia suggest that educational efforts devoted to promoting positive attitudes toward donation in the general population and specialized training for health professionals involved in organ procurement could both reduce refusal rates.[59] Another suggestion would be to convince families through motivational conversations with family members[60] or nudges.[61]

Combining arguments

The approach employed thus far asks, for any of the identified arguments in favor of the

[57] Burroughs, T. E. et al. (1998). The stability of family decisions to consent or refuse organ donation: Would you do it again?. *Psychosom Med*, 60(2): 156–162: 156–162; Haustein, S. V., & Sellers, M. T. (2004). Factors associated with (un)willingness to be an organ donor: Importance of public exposure and knowledge. *Clin Transplant*, 18(2): 193–200: 193–200; Murray, L., et al. (2013). Communication and consent: Discussion and organ donation decisions for self and family. *Transplant Proc*, 45(1): 10–12: 10–12.

[58] Ghorbani, F., et al. (2011). Causes of family refusal for organ donation. *Transplant Proc*; 43(2): 405–406: 405–406; Walker, W., et al. (2013). Factors influencing bereaved families' decisions about organ donation: An integrative literature review. *West J Nurs Res*, 35(10): 1339–1359: 1339–1359.

[59] Ebadat, A., et al. (2014). Improving organ donation rates by modifying the family approach process:. *J Trauma Acute Care Surg*, 76(6): 1473–1475: 1473–1475; Martins, S. S., et al. (2004). Pathological gambling, gender, and risk-taking behaviors. *Addict Behav*, 29(6): 1231–1235: 1231–1235; Mulvania, *et al., op. cit.* note 3: 2058–2065.

[60] Black, I., & Forsberg, L. (2014). Would it be ethical to use motivational interviewing to increase family consent to deceased solid organ donation?. *J Med Ethics*, 40(1): 63–68: 63–68; Shaw, D., & Elger, B. (2014). Persuading bereaved families to permit organ donation. *Intensive Care Med*, 40(1): 96–98: 96–98.

[61] Sharif, A., & Moorlock, G. (2018). Influencing relatives to respect donor autonomy: Should we nudge families to consent to organ donation?. *Bioethics*, 32(3): 155–163: 155–163.

family veto, whether it provides us with reason to disregard the wishes of the deceased and, second, whether it provides us with reason to locate the decision-making with the family. While this approach may convince us that neither of the arguments examined is sufficient to justify a family veto, this strategy comes with an important limitation. It is possible that some arguments, which in isolation are insufficient to provide an argument for the family veto, taken together could provide such an argument.[62] The final section examines this. The plausibility of this strategy is underscored by the fact that the examined arguments were unsuccessful in different ways and for different reasons. While the property-based argument failed in both tasks, the others fared better. The autonomy argument and the argument that we cannot harm the dead share an interesting similarity: While they provide reason to set aside the wishes of the dead, they did not provide reason for why the family's wishes should take priority. The consequential arguments were rejected because the empirical reasons to believe their truth were deemed too weak.

To assess the plausibility of combining these arguments, we will assess a combination of the concern for distress with the claim that we cannot harm the dead and the claim that ignoring the wishes of the dead does not infringe upon their autonomy. Each will be discussed under the assumption that the family veto substantially reduces the family's distress.

If, when the family uses their veto power, the deceased registered donor is not harmed and the family's distress is reduced, would we then have a convincing argument for the family veto? The combination provides both reason for setting aside the wishes of the deceased and reason for letting the family decide. But the combination of minimizing family distress and the idea that we cannot harm the dead raises another important difficulty: If no harm is done by vetoing the wishes of the dead, then no harm will presumably befall the dead if their organs are donated against their wishes. Minimizing distress under the assumption that we cannot harm the dead could seemingly include that the family can sanction donation despite the deceased explicitly opposing it.[63] This suggests that a combination of harm and distress is unable to deliver an argument for the family veto, because it justifies much more family influence than the family veto includes.

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[62] I owe this point to an anonymous reviewer, who stressed this limitation.

[63] Wilkinson raises this worry to distress based arguments for the family veto Wilkinson, T. M., *op. cit.* note 17: 68. See also, Wilkinson, T. M. (cited. note 40)

Consider, then, an argument combining the concern for autonomy and family distress. Zambrano argues that the non-removal thesis would not mean that people's autonomy is not infringed upon if we remove their organs against their will. The reason for this is the plausible suggestion that there is a crucial difference between failing to utilize what the deceased had consented to versus failing to respect that they have decided that their organs should not be utilized.[64] The combination of respecting autonomy and minimizing family distress is initially more promising than the combination considered above. It does not involve the justification of the family sanctioning donation against the wishes of the deceased. This is at least the case if we interpret it to mean that respect for the autonomy of the deceased trumps minimizing family distress. If we do not rank the concerns in this way, the problem of justifying too much would resurface, because minimizing distress could call for allowing the family to donate against the wishes of the diseased.

Adjusted like this, the combination is promising. It provides reason to set aside the wishes of the deceased as well as reason to let the family decide under the plausible assumption that doing so would minimize their distress. Nevertheless, the argument is unconvincing in terms of justifying the family veto; firstly, because while the combination avoids the weakness of the autonomy argument taken alone, it inherits the problems identified with the distress argument. The argument does not show that we should be exclusively concerned with the distress of the family rather than distress as such. As this is not the case, it remains problematic for the combined argument that, when the family employs their veto power, this is a source of distress for those who are waiting for organs and their families. As already argued, the focus on distress seems unable to justify the priority given to the family's preferences. For this reason, even if the combination of the autonomy concern and the distress concern is promising and indeed more promising than each of the concerns taken separately, it cannot support the family veto.

Conclusion

Arguments for upholding the family veto in cases of genuine conflict follow one of two paths: It is argued either that upholding the veto is in tune with some important value or that removing it would produce unfavorable consequences. In the first vein, proposals to

[64] Zambrano, *op. cit*. note 25: 199. See also Wilkinson (cited n. 37) : 587–90.

reconcile the family veto with ideas about organs as property as a way to prevent harm or to protect autonomy have been rejected. The property-based argument fails to establish that we should disregard the wishes of the deceased, whereas the arguments related to autonomy and harm fare better in this regard but still do not establish why we should give priority to the wishes of the family. In the more consequential vein, two different arguments to uphold the veto can be identified: One about avoiding family distress, which is ultimately unsuccessful because it fails to recognize the tremendous distress associated with waiting for an organ. The consequential argument is popular, but little empirical evidence supports it. Furthermore, accepting it as our sole reason for keeping the family veto would commit us to do much more to lower the family refusal rate. Combining distress with the arguments from harm and autonomy, respectively, also proved unable to justify the family veto.