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Title. Family Over Rules?

An ethical analysis of allowing families to overrule donation intentions

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Abbreviations

DR; donor register

ECMO; extracorporeal membrane oxygenation

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Abstract

Millions of people want to donate their organs after they die for transplantation, and many of them have registered their wish to do so or told their family and friends about their decision. For most of them, however, this wish is unlikely to be fulfilled, as only a small number of deaths (1% in the United Kingdom) occur in circumstances where the opportunity to donate organs is possible. Even for those who do die in the 'right' way and have recorded their wishes or live in a jurisdiction with a 'presumed consent' system, donation often does not go ahead because of another issue: their families refuse to allow donation to proceed. In some jurisdictions the rate of "family overrule" is over 10%.

In this paper we provide a systematic ethical analysis of the family overrule of donation of solid organs by deceased patients, and examine arguments both in favour of and against allowing relatives to 'veto' the potential donor's intentions. First, we provide a brief review of the different consent systems in various European countries, and the ramifications for family overrule. Next, we describe and discuss the arguments in favour of permitting donation

intentions to be overruled, and then the arguments against doing so. The ‘pro’ arguments are: overrule minimises family distress and staff stress; families need to cooperate for donation to take place; families might have evidence regarding refusal; and failure to permit overrules could weaken trust in the donation system. The ‘con’ arguments are: overrule violates the patient’s wishes; the family is too distressed and will regret the decision; overruling harms other patients; and regulations prohibit overrule. We conclude with a general discussion and recommendations for dealing with families who wish to overrule donation. Overall, overrule should only rarely be permitted.

Introduction

Across Europe tens of thousands of patients are on waiting lists for organ transplantation; an average of 11 people in need of an organ died every day in 2014, and at the end of that year 60,664 people were on the waiting list.¹ In the United Kingdom alone, three patients die every day waiting for an organ.² Many people have registered as organ donors in order to help potential recipients. But becoming an organ donor is not simply a matter of registering one’s intention to donate, and then eventually dying in a way that enables donation; it also requires that one’s family does not overrule donation. Most families are very distressed to learn of their relative’s death and cannot handle the idea of donation, expressing their opposition in a way that healthcare staff can find difficult to resist – even if regulations and legislation say that the wishes of the patient should be respected.

Consent and overrule: international context

Almost all countries allow some sort of overrule, regardless of the particular consent system in place in a given nation. The following section explores a number of European examples, and a summary is provided in Table 1.

In the UK, consent in advance to organ donation is most frequently given by joining the organ Donor Register (DR), an opt-in system that allows specification of which organs are to be donated. Although Human Tissue Authority guidelines state that registered donor wishes should be respected,³ health professionals tend to allow families to overrule donation. In the last year, 120 families (12% of approaches) overruled donation from a patient who was a registered donor, with the most common reason being that the time for the donation process was too long.^{1,4} Family overrule is three times more likely in donation after circulatory death, three times more likely in minority ethnic populations and three times more likely if there was no specialist nurse for organ donation involvement in the family approach.³ Under new donation legislation in Wales, an adult Welsh resident who dies in Wales will be deemed to have consented to donation, unless the patient has registered a decision to consent to donation, registered a refusal to donate, or appointed a representative to make this decision.⁵

In Switzerland, there is no national register, but residents can easily create an organ donor card that indicates which one of three options has been chosen. The first is donation, with details regarding which organs can be taken. The second is to register objection to any donation, effectively making the organ donor card an organ refusal card. The third is to nominate a representative who should be contacted and will make a decision in the event of a choice having to be made. Families frequently refuse and overrule donation in Switzerland; over 40% of donations are stopped by the family, although there is no data on how many of these are overrules.⁶

The Netherlands implemented the Organ and Tissue Donation Act in 1998, which is based on an opt-in system, supported by a national DR. Health care professionals consult the DR in case of a medically suitable donor before the relatives are approached. In the DR, Dutch residents can state their wish with regard to donation. The DR offers four options for organ and tissue donation: consent (with or without restrictions to specific organs or tissues); refusal; leave the decision to a specific person; or leave the decision to relatives in general. In 2014 families refused organ donation in 6% (11/175) of cases when consent was registered in the DR.⁷ According to the Dutch law an entry on the donor register does not have the same legal status as a will. For example, a will can only be modified or revoked by the testator, in contrast to the DR, where this rule does not apply.⁸ Therefore, families can - if they provide very serious reasons why the donation procedure cannot take place - overrule the consent given in the DR by the potential donor if they do not agree with the registered decision. This is based on the Explanatory

Memorandum to the Organ and Tissue Donation Act.⁹ The term 'very serious reason' is not defined in any official documents. There is an unwritten professional standard for situations like these.

On June 25 1997, the German Parliament approved a bill regulating organ transplants, the so called *Transplantationsgesetz*, which came into effect in December 1997 and is based on an opt-in system. This transplant act was updated in 2012. Post-mortem organ removal is allowed in different situations, one being when the potential donor has expressed consent. One can do this by stating wishes in a dedicated advance directive, but an informal written statement is also binding if signed by the donor. Another possibility is an organ donor card on which a person can state consent or objection, or leave the decision to a particular person. There is no national registry.¹⁰ In cases where no document exists, families are asked whether they know about any statement of the deceased. The families must have had contact with the potential donor in the last two years before his/her death, to be able to know about a statement or his/her attitude concerning organ donation.¹¹ . If relatives do not know about the will of the deceased, they are allowed to take a decision on basis on the relative's own moral concepts, taking into account the presumed will. If they were not in contact or there are no direct relatives, a close friend can do this instead. If there are documented intentions or an organ donor card with the expressed will to donate organs (or tissues), the relatives (or friends) cannot normally overrule the decision of the deceased. His or her decision is legally binding; the organ donor card is equal to the last will.¹² But there may be a situation where the organ donation is not carried out,

because the relatives refused. This can be the case when an organ donation is perceived as risking severe psychological trauma to the relatives.¹³ (The law does not state that relatives cannot overrule donation, but this is implied by the status of the recorded donation intentions as a last will.)

Austria has a strict presumed consent system, with a national registry to record objections. Besides objections documented in this registry, any other form of declaration of a deceased person's will regarding post-mortem organ donation (for example an informal document found among the identity papers of the deceased or an oral declaration made in presence of the family) is respected. Under Austrian law family members of the deceased are not entitled to object to organ donation.¹⁴ However, in practice the family members can overrule the wishes of the presumed donor.

Spain was one of the first countries to implement organ donation legislation. The 1979 Act Nr.30/1979 provides for an opt-out system: removal of organs is permitted when the deceased has not made an objection. Objection to organ donation can be expressed in any way, without formal procedures. To establish if there is an objection, several steps can be taken, such as inspection of the medical file, search of personal belongings and/or asking the family. According to some commentators, presumed consent equates simply with the presumed consent of the potential donor – the actual decision to donate is up to the potential donor's family.¹⁵ The family can base its decision on many factors, for example on the expressed wish of the deceased.

Belgium operates a similar system to that of Austria; organs will be removed unless an objection is recorded in the national registry.¹⁶ Families can overrule donation if there was no recorded wish to donate, but there is no need to inform them about donation.¹⁷

Arguments in favour of the family overrule

In this section we set out and analyse six arguments in favour of the family overrule. In summary, those who support letting families overrule a recorded wish to donate argue that doing so can reduce their distress and minimise stress for healthcare staff; in addition, donation cannot proceed without practical information being provided by families. Proponents of overrule also argue that families might have new information about a patient's refusal to donate, that going against the wishes of families could weaken trust in the donation system, and that too much emphasis can be placed on respecting the wishes of the individual.

Minimising family distress

The main argument in favour of allowing families to overrule established donation intentions is to minimise their distress. Almost all families in this situation have been very recently (or are just about to be) bereaved, and can be extremely upset even before donation is mentioned. To proceed with donation in the face of a strong objection from a family member might make a difficult situation even more distressing for them (even if any such objections may sometimes stem more from the fact that they are already upset than from

a deeply held belief). This argument is particularly relevant for families (and countries) that place particular importance on respecting the body after death.

Minimising staff stress

A second, related argument is that proceeding with donation and risking further upsetting families also places great strain on healthcare staff, who must witness this distress and may feel guilty about exacerbating it – or for being responsible for it. It is understandable that doctors, nurses and transplant coordinators find it difficult to challenge family reluctance or refusal to donate organs, as doing so can cause psychological stress.

Practical cooperation

A third argument is that donation requires the practical cooperation of the family. Families are an essential source of information regarding any recent illnesses or medications that might affect the likelihood of successful transplant; if an attempt to overrule donation is ignored, families are likely to refuse to cooperate with these practical checks.

New information regarding refusal

A fourth, related argument is that the family may have new information about their relative's willingness to donate. Any recorded wish to donate is normally disclosed to the family in case the potential donor had changed his or her mind since registering an intention to donate – for example, a patient could have signed up to be a donor decades before, and subsequently changed her mind but never removed his or her name from the donor register. In addition,

the family may be able to offer valuable input regarding assessment of whether donation and associated interventions are what the patient would have wanted in the circumstances that are occurring.¹⁵ (It should also be noted that families might question whether ticking a box on a driving licence application is sufficient for informed consent to donation.¹⁸)

Undermining trust in system

A fifth argument is that going against families' wishes could undermine trust in the donation system. If there were media coverage of cases where families' attempts to overrule were unsuccessful, it could lead to many registered donors removing their names from the register, or registering an objection to donation, and ultimately to a lower number of donations and transplantations than would have been possible had the families in question been allowed to overrule. However, the converse is also true; allowing families to claim that the patient had changed his or her mind could also weaken trust in the organ donor system, if potential donors lose confidence that their wishes will be respected.

De-emphasising the individual

Finally, a related cluster of arguments concerns the idealisation of the individual. It can be argued that placing so much emphasis on the individual wishes of the deceased or dying patient idealises the independence of the person and neglects the relational nature of social persons everywhere.¹⁹ An ethical argument flowing from this point might be that the decision is not in

practice that of an individual alone to make and that we should pay closer attention to the effects on others of our actions and wishes.

Arguments against the family overrule

There are also at least five arguments against allowing families to overrule donation. In summary, these are as follows: the overrule disrespects the wishes of the deceased patient; allowing families to overrule when they are upset about the death of a relative is unfair, and they can soon come to regret overruling donation; each overrule means that several organs are not transplanted which could have been, leading to prolonged suffering and sometimes deaths of potential recipients; and the legislation and regulations in many countries is that donation intentions should be honoured.

Violating the wishes of the deceased

The first argument is that permitting a family overrule violates the wishes of the deceased; if someone was a registered donor, this is clear evidence of an intention to donate, and that his or her intentions should be respected.

Ignoring the “dying wish” of a patient can be seen as dishonouring the deceased. It should be noted, however, that while registration is *evidence* of consent to donation, it cannot automatically carry the same weight as consent elsewhere in medicine where greater efforts to inform the patient are made. It should also be noted that the distinction between opt-in and presumed consent systems can affect the weighing of evidence in this context. An active registration of an intention to donate will normally be regarded as stronger

evidence of a wish to donate than the absence of a refusal to donate in a country that operates a presumed consent system. In the latter case, a family could claim that their relative was unaware that failure to declare an objection constitutes consent to donation.

Placing a burden on families

Another argument against permitting families to overrule is that it is unfair to expect families to make this decision when they are already so distressed about the loss of a loved one. Making a decision about whether to object to donation places a considerable burden on families, who might instinctively refuse donation because they are so upset. This could lead to the decision being an impulsive one that fails to reflect their (or the deceased patient's) settled values rather than the emotions that are dominant at this very stressful time.¹⁷ It is understandable that staff don't want to upset families further, but it is not wise to give families the opportunity to go against the wishes of their deceased relatives when they are already distressed and are likely to make a potentially rash, highly emotional decision. Furthermore, families in this situation are subject to many biasing factors that can be addressed (lack of knowledge about benefits of donation; belief that patient will suffer if donation goes ahead; misunderstanding of brain death, etc²⁰). Therefore, in many cases it would be responsible to consider the family's best interests in the medium to long term rather than simply granting an attempted overrule.

Coming to regret the overrule

The third argument against permitting overrule is very closely related to the previous one: families can come to regret a decision to overrule donation. This is unsurprising, given that such decisions are often made in very challenging circumstances. In addition, many families who permit donation feel that helping others via transplantation is a “silver lining” to the death of a relative; families who override deny themselves this small solace, and some relatives may also regret failing to respect the wishes of their dead relatives and/or not helping potential recipients. Evidence from a Brazilian study suggests that the regret often experienced by families who override donation may lead to a change of heart: even in cases where there was no registered intention to donate, over 50% of families who refused to allow donation would subsequently permit it in similar circumstances.²¹

Contribution to avoidable harm

In addition to the three main arguments concerning the potential donor’s wishes and the role of the family, there is another key reason to prevent overrule of donation intentions: each overrule contributes to avoidable harm. Each overridden donation means that several organs are lost from the pool of organs; this in turn means that potential recipients must wait longer for organs, and this wait will often result in avoidable deaths. Even if patients do not die, the wait can be detrimental to their overall health and well-being. In other cases patients will die as a direct result of donation intentions being overridden. Although it is understandable that healthcare staff want to avoid further distressing families, it is also important to consider the consequences

of allowing overrule, though many doctors will be reluctant to mention these consequences to families.²²

Regulation and legislation

A more technical argument against the overrule is that the laws and guidelines governing donation in many jurisdictions make it clear that the patient's wishes should be respected. In England and Wales, the Human Tissue Authority Code of Practice on Donation¹³ makes clear that where an adult made a decision to, or not to, consent to organ donation taking place after their death, then that consent is sufficient for the activity to be lawful:

Once it is known that the deceased person consented to donation, the matter should be discussed sensitively with those close to the deceased. They should be encouraged to recognise the wishes of the deceased and it should be made clear, if necessary, that they do not have the legal right to veto or overrule their wishes. There may nevertheless be cases in which donation is considered inappropriate and each case should be assessed individually [102].²³

The new version of this Code, to be published in 2017, is more strongly worded, specifically stating that "A relative's objection does not nullify appropriate, valid consent from the prospective donor."²⁴

Discussion

There are a number of key arguments in favour of allowing an overrule, and a number of key arguments against doing so. The opinion of the ELPAT

Deceased Donation Working Group is that enabling families to overrule disrespects the wishes of the deceased, can be regretted by families, and contributes to avoidable death and suffering. The potential harms of permitting an overrule are greater and more serious than the potential harms of not permitting one. Therefore, we conclude that a registered intention to donate should generally be respected, regardless of objection from the family, unless their objection is that the deceased had changed his or her mind since registering as a donor (or was unaware that a presumed consent system was in operation). Any such claim would not really be an overrule, but new evidence of a refusal to donate. In some limited circumstances, however, it could be argued that the interventions necessary to make donation possible, or the long wait that families must endure, constitute potential additional reasons for respecting a family's wish to overrule. Whether it is ethical to permit an overrule in such cases will depend on the balance between the strength of evidence regarding the donor's consent to donation and the level of intervention that would be required to make that donation happen.

We must also consider the real-world implications of attempting to stop all overrules, and whether the practical consequences of following such a rule in practice could be counterproductive. On a basic level, a family opposed to donation might simply claim that the deceased's wishes had changed. The family might do so if they wanted to prevent donation but knew that admitting he or she still wanted to donate would make an overrule impossible. Ignoring the wishes of families could also make intensive care unit (ICU) staff less likely to be willing to explore donation with relatives in the future, and could

weaken trust in the organ donation system by alienating potential donors. For example, someone who is currently on the organ donor register might withdraw consent to donation if it were made clear that families will have no input to the process. Families with strong objections whose wishes are ignored might contact the media, resulting in damaging press coverage of a vital part of any national healthcare system and a wider decrease in the number of people registered. (Equally, of course, allowing families an “easy overrule” could also result in donors losing trust in the system.) In addition, ignoring families who claim that their loved one had changed their mind about donation could actually result in the removal of organs from someone who had really changed her mind. If these consequences flowed from changing to a strict no-overrule system, the change would be unethical. Equally, however, simply allowing families to continue to veto unimpeded would be unethical.

So what is the best way forward? We suggest that the solution is to continue to permit overrules in very particular circumstances, whilst working towards modifying the circumstances that may lead to an overrule being considered in the first place. There are several strategies that can be used to discourage families from overruling.

One of the simplest strategies is to encourage everyone who signs up to an organ donor register to talk to his or her family and friends about their decision and stress how important donation is to them. Of course, some people might well be happy for their family to overrule if distressed and this could be communicated too. This strategy has the advantage of involving relatives and

friends well before the event that makes donation possible, meaning that they are not presented with the information only after (for example) a car accident. However, one disadvantage of this strategy is that people may forget to talk about this, or will question whether a person's intention to donate persisted over several years or decades after the conversation about donation. This problem about persistence of wishes also applies to "old" donor registrations. One potential tool that would avoid this problem is the personalised organ donation directive, a type of advance directive that asks donors to reaffirm their intentions every year and also allows them to send video messages to relatives before or after death.^{25 26} Or, more simply, organ donor registers can be created with the ability for individuals to record a written personal message (see below).

In some cases, families will remain unaware of or unconvinced by their relative's wish to donate. In such circumstances another potential strategy is to ask them (without coercion or manipulation) to respect the wishes of the deceased.¹⁷ This option has the advantage of directly addressing stated reasons for the overrule, but also the disadvantage of further upsetting families when they are already distressed by the death. In the United States, attempts to prevent families overruling donation have gone as far as the courts, with court cases resulting in judgments against the families.²⁷ US federal law states that "a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part if the donor made an anatomical gift of the donor's body or part."²⁸ We would not recommend pursuing such a hard-line approach, for the practical reasons

mentioned above. A related strategy is to ensure that healthcare staff themselves are always aware of the importance of facilitating donation, which must also include at least investigating any attempt at overrule. Good interaction between professionals and family members is essential to the donation process.

A final option to consider is ensuring that the system for registering intent to donate is as flexible as possible, so that potential donor's wishes can be accurately reflected. More robust and personalisable systems of consent could help to inform families and healthcare professionals about when an overrule might be permissible (e.g. where donation involves highly technical measures such as in situ extracorporeal membrane oxygenation (ECMO) or will take several days). As stated above, in summer 2015 the UK made changes to the register to allow people to register an objection to donation. However, an opportunity was missed to enable people to indicate consent to donation but also state that it would be or would not be acceptable for a relative to overrule. Furthermore, the new register might have allowed donors to record a short message that could be shown to family members if donation becomes an option - similar to, but more basic than, the personalised directive mentioned above. Implementation of each of these measures would make it more likely that registered donation intentions accurately reflect the genuine wishes of donors (or refusers), and in turn increase the likelihood that these wishes will be respected by family members or friends. Our suggested strategies are summarised in Table 2; in essence, we recommend

encouraging donors to communicate, ensuring that professionals challenge overrules, and enhancing consent systems.

One other point that should be clarified concerns an apparent asymmetry. The status quo is that families who have serious objections can overrule donation; this has been the focus of our discussion. But can families also overrule a registered objection to donation? At first glance this might seem to be an appealing argument, because overruling an objection could save or improve the lives of potential recipients. In contrast, overruling a wish to donate can deprive recipients of organs, leading to suffering and death. But there is a key legal and ethical difference between giving consent to permit organs to be taken if circumstances permit it, and refusing to donate organs under any circumstances. In the former case, consent legitimises the removal of organs, but does not mandate it. In the latter case, refusal would normally not be contingent upon circumstances in the same way as consent. In other words, the “yes” to donation is permissive, while the “no” refusal to donate is more prescriptive. This key difference parallels the consent/refusal distinction elsewhere in medicine. If a patient consents to treatment, there is not any obligation to provide that treatment; but if a patient refuses a particular treatment or intervention, it would be battery to ignore that refusal. In the case of organ donation, the patient’s interest in her bodily integrity post-mortem may be weaker than it is during life, but the refusal to donate nonetheless seems to be more powerful than a consent to donation. There are also two other reasons why the seeming asymmetry might in fact be justified. Families are sometimes permitted to overrule a consent because they are distressed at

the idea of donation, but families are unlikely to be upset at the idea of not going ahead with donation if they know donation was not what the patient wanted. Similarly, it seems plausible that they are less likely to come to regret failure to overrule an objection than they are to regret failure to overrule a recorded consent to donation. Indeed, they might actually come to regret overruling an objection because they failed to respect a loved one's dying wish to have his or her bodily integrity respected. For all these reasons, it might be appropriate to permit overrules of consent in some cases, but never to permit overruling of registered refusals unless convincing evidence can be provided that a recipient had really changed his mind and wanted to donate. Exploring these issues in greater depth is outwith the scope of this article.

Conclusion

Every country in Europe allows some type of family overrule in practice. There are strong ethical arguments in favour of preventing families from overruling a known intention to donate. These concern not only autonomy, but also the potential benefit to other patients of receiving organs, and the regret that can be felt by families who overrule donation. However, there are several reasons why overrules are sometimes acceptable. Current registration systems across Europe are fairly basic, meaning that donors cannot indicate nuance regarding their donation wishes beyond which specifying which organs they wish to donate; there are some circumstances in which families provide

evidence of a change in donation intentions; and there are some limited cases in which the donor would not have consented had he known the specifics of the particular organ donation scenario in question (such as the long waiting period before donation or use of ECMO, etc). Ultimately, adopting a hard-line no-override system could have detrimental consequences for donation systems and donation rates. Therefore, the best option appears to be asking families and friends to respect donation intentions, through adoption of more effective strategies both before and after death.

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