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When is directed deceased donation justified? Practical, ethical, and legal issues

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Abstract

This paper explores whether directed deceased organ donation should be permitted, and if so under which conditions. While organ donation and allocation systems must be fair and transparent, might it be "one thought too many" to prevent directed donation within families? We proceed by providing a description of the medical and legal context, followed by identification of the main ethical issues involved in directed donation, and then explore these through a series of hypothetical cases similar to those encountered in practice. Ultimately, we set certain conditions under which directed deceased donation may be ethically acceptable. We restrict our discussion to the allocation of organs to recipients already on the waiting list.

Keywords

Organ donation, directed deceased donation, ethics, law, family

Introduction

Laura Ashworth, a 21 years old woman in the United Kingdom had allegedly planned to donate her kidney to her mother who was on hemodialysis. At the time of Laura's death she had not started the formal process for living donation. The Human Tissue Authority (the regulator in the United Kingdom) statement at the time was that: "The central principle of matching and allocating organs from the deceased is that they are allocated to the person on the waiting list who is most in need and who is the best matched with the donor. This is regardless of gender, race, religion or any other factor."[1] Laura therefore donated her organs to strangers. One year later Laura's mother died having never received a transplant, leading to headlines such as, "Mother dies a year after being denied her daughter's kidney."[2]

The persistent shortage of organs available for transplantation demands fair and objective allocation of the scarce available organs, based on preset transparent and regulated criteria. In most European countries, organs from deceased donors are allocated to patients on the organ waiting list by national Competent Authorities.[3] The current worldwide norm is that organs donated after death are considered as an unconditional gift to the patients on the transplant waiting list according to the allocation system. This implies that donors (prior to their death), or their family members (after it), cannot determine to whom the available organs will be assigned, nor exclude any potential recipients.

However, in recent years, medical professionals have been confronted with requests from families to donate one organ from their deceased loved one to a family member or good friend waiting for an organ. Occasionally, people who intended to become living donors die and become potential candidates for deceased donation before their intended living donation could be carried out, which can also result in a request to make sure the intended recipient receives the organ as intended. Allocating an organ to a specified person after death is called "directed deceased donation" (DDD). In this paper, we do not use

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the term to refer to direction to a specific *group* of people, as some authors have done in the literature.

Granting such requests to deviate from the, so far generally accepted, organ allocation rules in such exceptional, emotional and familial cases seems understandable. Although the number of cases over the last years are very small, and therefore the impact on the standard allocation seems negligible, permitting such requests could impact on the perceived fairness of the deceased donation system.

In a few countries, like the United States, United Kingdom, Japan, and recently Australia, directed deceased donation is possible in restricted cases, since national legislation does not prohibit it. In living donation however, directed donation is permitted in many countries, even when there is no genetic or emotional relationship between the donor and the intended recipient. This inconsistency between the living donation- and deceased donation system has been noted.[4]

This paper explores whether directed deceased donation should be allowed, and if so under which conditions.

Legal background

In general, directed deceased donation is not permitted by national legislation. All over the world, governments have installed legal systems to aim at equal access and fair allocation of the scarce organs. In practice this means that all available organs are reported to a (national) coordination center, which allocates the organs to most suitable recipient based on medical criteria, and other preset conditions like waiting time, distance, or when allocated in an international setting, country balances.

There are so far five exceptions of which we are aware:

> In the UK directed deceased donation became possible after the Human Tissue Authority (HTA), the statutory regulator of organ donation and transplantation, softened its position following the high profile case of Laura mentioned above. NHS Blood and Transplant, the national donation and transplantation organisation responsible for allocation, updated its policies to allow directed donation of a deceased donor organ. The Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006 offer room to adapt allocation in such a way that directed deceased donation is allowed under the condition that additional new allocation policies are clear, simply expressed and well understood by family and friends who are making requests at a time of high stress.[5,6] In a policy document agreed upon by all UK Health Administrations, a detailed framework for a request to allocate a deceased donor organ to a relative or close friend has been described.[7] Taking into account the two overarching principles of "absence of conditionality" and "equitable treatment," direct deceased donation may be considered in case of the death of an intended living donor, or if there turned out to be a relative or very close friend in need of an organ. However, the guidelines also state that urgent clinical need of a patient on the waiting list should always prevail.

Another exception is the USA, where DDD is defined as "a request made by a donor (during life) or donor family to transplant to a specific recipient" is legally authorized by the Uniform Anatomical Organ Gift Act UAGA at least since the late Sixties and by most anatomical gift laws, which use UAGA as a guide. The national Organ Procurement and Transplantation Network (OPTN),[8] operated by the United Network for Organ Sharing (UNOS) under federal contract, accepts directed donations as long as the responsible agencies verify the medical suitability of the organ offer to the intended recipient.

In Australia the donation of deceased donor organs is considered an unconditional altruistic act. Deceased donor organs are allocated to the most suitable people by the assigned authority. The National Health and Medical Research Council stated in 2016 that "It is not ethically appropriate for a donor, through previously expressed wishes, or the family of a deceased person to impose conditions on organ donation or to specify potential recipients."[9] However, the Council also stated that under certain conditions it is ethical for DDD to proceed:

> when there is evidence that the person was prepared to be an organ donor after death, and there is evidence (e.g. through a living will, advanced care directive or prior planning with a transplant team) that the person expressed a preference for certain organs to be donated to a close relative in need of a transplant under the conditions that the potential recipient is considered eligible for transplantation and consents to receiving organs from that donor.[9]

In Canada, prior to the introduction of donation after medical assistance in dying, directed deceased donation was allowed in one province (Ontario): In very rare circumstances, Ontario Trillium Gift of Life Network (TGLN, now subsumed under Ontario Health) permitted directed deceased donation on a case-by-case basis.[10] Each case had to meet the following criteria:

- The designated recipient is a family member, or an individual with a long-standing emotional relationship;
- The donation will still proceed if directed donation cannot be realized;
- There are no other patients in urgent clinical need of the organ;
- The intended recipient is on the wait list or meets the listing criteria; and the donor organ is medically compatible for the intended recipient.

In Japan DDD is allowed in the revised Organ Transplant Act,[11] but only to parents and (adopted) children, married spouses if they are on the transplant waiting list, and there is a written declaration of this intention of the donor to direct the organ to the specific recipient.

Frequency of DDD in different countries

The information in this section is based on the expertise of several of the authors.

Over the last few years Competent Authorities responsible for the allocation of deceased donor organs have

been asked on several occasions to permit directed deceased donation. However, there is a general lack of reliable evidence on the frequency of DDD requests and proceeding cases. Most requests were made by the next of kin of the deceased, representing the "assumed wish" of the deceased or their actual wish. In the majority of cases the request was for a family member, but at least in one case in the Netherlands one of the next of kin needed the organ herself. In the UK, also, cases have been reported. In other countries it is often difficult to collect these data, since in most countries it is not allowed and therefore the possible requests are not reported.

In the Netherlands, the organ donation law does not allow direct deceased donation and no formal register of requests is kept. In recent years there has been around one request for DDD per year in the Netherlands (relative to approximately 270 deceased donors in total each year), but families may be reluctant to make a request if the intended recipient is not (yet) on the waiting list for an organ. All requests however, had to be turned down since in all cases the donation occurs after death and therefore the Dutch law applies, which does not allow DDD.

In the Scandinavian countries there have been no reported cases of directed deceased donation. In Spain the law prohibits DDD but requests have occurred in the past.

In the UK, very few directed deceased donations have occurred in the UK as the exact clinical situation which arises seldomly matches the policy requirements (and the perception was that there is always a "more urgent" patient in need of the organ). There is current internal discussion about how the policy can be changed to more liberally allow directed deceased kidney donation in the UK.[12]

Ethical analysis

Conditional donation such as DDD raises several ethical issues.[2] Permitting directed donation could increase donor autonomy, and would bring deceased donation more into line with living donation protocols where directed donation is permitted. But as noted by Cronin and Douglas,[4] DDD might be seen as compromising the impartiality and integrity of existing organ allocation systems. In this section we provide a systematic list of arguments for and against DDD.

Arguments for DDD

The first argument for permitting DDD is that it could increase the potential scope of donor autonomy by enabling them to direct an organ to a family member or friend if that is what the person would have wanted if they were in a position to be consulted. For a minority of deceased donors, this provides an opportunity to help a family member in need of an organ, rather than donating to unknown persons on the waiting list. This is only possible if the intended recipient is a "match" for the donor's organ.

This leads on to the second argument: in living donation, direction to a family member is permitted in many countries, resulting in an asymmetry between the living and deceased donation systems. If living donors are able to exercise their autonomy in choosing to donate to a family member, even though that poses medical risk to them and despite the risk that they might feel obliged to do so, why should a deceased donor (who is at no medical risk) not be able to do so? Permitting DDD would remove this asymmetry between the two systems, as currently we do allow donation to a specific person during life, but we do not allow this after death.

A third argument in favor of DDD is that it could increase the number of donors[13]; some people might refuse to donate unless they can direct an organ to a relative. Besides the specified person, other patients can be helped with the other organs from that specific donor. Evidence suggests that DDD can also increase the number of people willing to become a donor.[14] Although there is an ongoing discussion on whether organs are owned by an individual person, for many people it feels reasonable to have a say on what will happen with parts of your body. DDD would motivate these people to donate and should be permissible under the condition that the donation is unconditional (if the desired individual is not a match, donation would still go ahead, helping the pool of patients waiting).

A final argument for DDD is that in many populations across the world it is culturally accepted that needs of the family should be prioritized, which aligns with allowing DDD to close family members. According to Glannon and Ross[15] there could be a special obligation to family; if there is a relationship there may be expectations and obligations; based on shared needs and interests. And given the sad situation in which donation takes place, it is conceivable that donation to a close family (or friend) in need of a transplantation may help to relieve or even reduce the grief of the next of kin. Given that families are an integral part and trusted of the donation process, requests for DDD should not be dismissed out of hand simply because organ systems strive to be impartial.[16] This is all the more applicable in certain parts of the world and certain minorities in Western countries where even greater emphasis is placed on the importance of the family.[17] Furthermore, if families cannot use the death of a loved one to save the life of another relative via DDD, this means there is a risk they will suffer the consequences of experiencing two deaths instead of one. Permitting DDD could also have a positive effect on healthcare professionals, who in many cases perceive it as unfair that they cannot help families be facilitating directed donation.

Arguments against DDD

The main argument against DDD is that this violates the basic principle of an altruistic, unconditional gift to society; allowing DDD may turn out to be a "slippery slope" in the direction of conditional donation and discrimination against particular patient groups. Conditional donation could also reduce public support for the transplantation system, since it could reduce transparency and fairness of the system.[18] One measure that could be taken to ensure at

least some unconditionality would be to require donation of at least one other organ along with the one intended for DDD, assuming that this is medically possible. This would enable direction to the intended recipient while preserving the "gift to society" aspect of donation (Of course, directed living donation is highly conditional, without this extra requirement; but in that case the donor is running a substantial risk by donating.).

A related concern is that DDD may also induce inequity, or even discrimination against individual patients, since DDD allows some individuals access to organs, bypassing other individuals in need of an organ. If a donor is permitted to direct an organ to a family member, someone on the waiting list may have to wait longer for an organ as a result. While it is understandable that people want to help their families, justice is an essential part of biomedical ethics, and moral distance from unidentified people on the waiting list should not result in their effective deprioritisation. If DDD is restricted to close family, those with large families are in a much better position than those who have small or no family around. Justice should prevail when resources are scarce; therefore the donation system should be fair and egalitarian.[19]

However, these objections also apply to living donation, where people who have larger families or are more socially connected are much more likely to find someone to donate an organ to them. If directed living donation can proceed in the face of these concerns, why should deceased donation not operate in the same way? These cannot be fundamental objections or directed living donation would also have to cease. While it might seem unfair to those on the waiting list to permit DDD, does it seem fair to deceased donors to deny them this opportunity to help their families?

Fairness and justice in DDD

To some extent arguments for or against DDD depend on which perspective on justice is adopted. If one applies an entirely impartial model of justice where organs must be allocated to those in greatest need, then DDD is unjust.; However, given the importance placed on the role of the family in society, it also seems unjust to treat family members as simply being other citizens; this is "one thought too many," as suggested above.[20] On balance, it appears that DDD can be "partial but not unfair," as suggested by Hillhorst.[21] Of course, care must be taken that DDD does not open the door to discriminatory conditionality such as racism.

It can be argued that these benefits are understood and supported by other patients on the waiting list as mentioned by Volk and Ubel[18]: "Relationships have shaped human behavior over the course of history, so it should outweigh the concerns about fairness and waiting times; it is also very understandable for other patients on the waiting list" and for healthcare professionals. However, it remains possible that some potential donors might object to DDD on fairness grounds and remove their names from the register.

In addition, deceased donation is not really unconditional in any case; donors can say which organs they do and do not want to donate, and families can impose further limits on which organs can be transplanted. Could it be that we permit directed living donation because banning it would seem unfair to donors who remain alive, while banning DDD is only unfair to dead donors? In both cases, potential recipients are allocated organs which may be to the detriment of others in need of organs, or unfair; yet in one case the donor remains alive (Furthermore, in some countries the public endorse imposing of conditions on organ donation.[22]).

Considering the very low frequency of DDD, even if it is permitted more widely under limited conditions, this will hardly disturb the allocation system of deceased donor organs.

Hypothetical case examples

Having discussed the general ethical arguments, we will now explore more complex ethical issues raised by a series of hypothetical case studies. This analysis will enable us to establish more precisely the conditions under which DDD is ethical, and those under which it should remain impermissible. For all the cases described below the donor was medical suitable for organ donation. DDD cannot be used to force a transplant team into performing a donation that they would not otherwise consider.

> *Case 1: a male patient had kidney disease and his wife wanted to donate her kidney in a living donation procedure. She died unexpectedly before this was possible, and became a potential deceased organ donor. The medical team wondered whether directed deceased donation might be possible in this case.*

In this first case, the husband would have received his wife's kidney if she had not become a potential deceased organ donor. Here, the asymmetry between living directed and deceased directed donation is stark; her husband needed a kidney, she was willing to donate it, and that would have been perfectly acceptable under most living donation systems. However, because she was unfortunate enough to die, the rules change and donation can no longer go ahead, meaning that the husband not only loses his wife but also an opportunity to get a kidney transplant. In such cases, it seems very reasonable to permit DDD; the kidney would go to the husband as intended and the organ donation system also benefits from other organs being donated.

> *Case 1b: a male patient had a kidney disease and his wife wanted to donate her kidney in a living donation procedure. She died unexpectedly in an intensive care unit before this was possible, and the medical team wondered whether directed deceased donation might be possible in this case. The male patient (potential recipient), however, is seriously unwell and there is a high risk of transplant failure.*

In cases where there is a high risk of transplantation failure, using DDD as a backup to living donation may not be appropriate if the organ could instead go to someone on the waiting list with a higher likelihood of successful transplantation. This may also be the case in other types of DDD.

> *Case 2: a man suffering from a devastating brain injury is admitted to the ICU, where treatment becomes futile and will be stopped. Therefore, his death is expected. He is a registered organ donor and his wife is on the waiting list for a kidney. She asks whether she could have one of her husband's kidneys and says that's what he would have wanted.*

In this case, it does not seem unreasonable for the widow to request a kidney. However, this differs from the first case. In Case 1 the kidney was intended for the spouse if everything had gone as planned. In Case 2, the kidney was never intended to come to her, and if deceased donation went ahead as normal would benefit a stranger on the waiting list; likely a stranger who had waited longer and was in more clinical need. In such a case, it would be helpful if there were evidence that the husband wanted to donate to his wife (just like Case 1), perhaps from a general practitioner or transplant team about any intended discussion. If we assume however, that this is what the husband would have wanted (and normally we are very willing to accept other statements from the family of patient intention in life regarding donation), the question remains whether it is ethical to "divert" the organ in this way. As in the first case, this was an expected death, and the organ donation system will receive all the other organs. Would it be unfair to grant the widow's request? In the sense of objective distributive justice, it might be unfair, but it would also be unfair on the individual level not to let a person direct an organ to a relative if he dies.

> *Case 2b: a man dies unexpectedly after admittance on the intensive care unit. He was a registered organ donor and his friend is on the waiting list for a kidney. The friend asks whether he could have one of the deceased's kidneys and says that's what the patient would have wanted.*

This case is very similar to the previous one; only the relationship between the would be recipient and the deceased is different. As such, it may be more speculative to say that this is what the deceased person would have wanted. But if evidence can be provided to back this up, then DDD may be justified. More challenging are cases where the designated recipient is not a family member or friend but a celebrity, as in the case of Nathalie Cole.[23] Here, social justice concerns might outweigh the advantages of DDD as it would be unjust if people were prioritized for organs because they are famous.

> *Case 3: a female patient knows she will die soon (euthanasia for a terminal brain tumor) and requests that her heart goes to her husband, who is on the waiting list to receive a transplant. However, he is not yet in "urgent" need of a heart and others on the waiting list are in greater need.*

Let us put aside the objection that the female patient is ending her life to save her husband and let us accept this is just a tragic situation for all concerned. Here the request for DDD may seem more difficult as it is clear that letting the heart go to the husband when the wife dies would disadvantage, even risking the life, of someone on the waiting list. However, even here it is not so clear. Many donors and their families refuse to donate certain organs, and there is no expectation that all donors donate their heart. Given this, and given the patient's clearly expressed wish to help her husband, and the fact that she will also donate all her other organs, DDD also seems justified in this case (In the UK survival of "urgent" patients who never get a heart transplant after 3 years is 10%, while it is only 5% for non-urgent patients—indicating that the margin of difference in terms of urgency is really marginal.[24]).

Conclusion and recommendations

From the analysis of the cases discussed above, we conclude that DDD should be permitted under certain conditions. From case 1, we concluded that DDD should be permitted in cases of thwarted living donation where the intended donor dies unexpectedly. From case 1b, we added the caveat that DDD may not be appropriate where there is a high risk of transplant failure in the intended recipient. In cases 2 and 2b, we concluded that DDD to a family member or friend should be permitted where there is evidence (or it is believed) that that this respects the intention of the donor. And in case 3 we concluded that even if there is a patient in greater clinical need or an organ such as a heart, DDD should be permitted.

What, then, are the conditions for ethical DDD at the present time?

1. DDD under strict conditions should not be prohibited by legislation or policy.
2. There must be evidence that the donor wanted or would have been willing to direct the organ to a particular family member or close friend.
3. The donor/family should generally not be able to insist on only donating the organ intended for DDD; where other organs are transplantable there should be a willingness to donate other organs (at least one) to patients on the waiting list to preserve the societal altruistic aspect of donation and diminish the overall effect on the waiting list.
4. DDD should proceed only if there is no patient on the waiting list in extremely urgent need of an organ transplantation to avoid imminent death.

5. DDD should proceed only if there is a reasonable chance of successful transplantation.
6. The intended recipient should be on the waiting list or be under assessment for being included.

If these conditions are met, the medical team should do their best to facilitate the wishes of the deceased patient and his/her family by enabling DDD to take place. Letting deceased donors direct their organs to loved ones under carefully controlled conditions could further enhance trust in organ donation and transplantation systems, and hence willingness to become a donor.

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